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LIFE AND DEATH IN ICU: NURSING CARE TO SMOOTH TRANSITIONS FOR PATIENTS AND FAMILY

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University of Plymouth

**LIFE AND DEATH IN ICU:
NURSING CARE TO SMOOTH TRANSITIONS FOR PATIENTS AND FAMILY**
by
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A thesis submitted to University of Plymouth
in partial fulfilment for the degree of

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AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Doctoral College Quality Sub-Committee.

Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

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ABSTRACT

Background

Nurses are the clinicians closest to the patients in daily monitoring of processes and adaptations: assessing, intervening with treatments and evaluating the outcomes. Nurses evaluate all physiological abnormalities, emotional instabilities as well as spiritual requirements regarding religious beliefs, cultural rituals and family relationships.

Aim

This thesis examines the context, purpose, significance of life threatening and end-of-life situations in critical care and demonstrates the integral work of nurses in calming, organizing and making sense of intensive care unit life and death conditions.

Program of work

The body of work reported in this thesis comprises a collection of work resulting in the creation of an end of life care bundle. Each segment of the bundle is organized into evidenced based critical junctures. The first critical juncture is an appraisal of responsiveness of patient's disease process to curative interventions applied in the ICU. The second critical juncture looks at shared decision making, coping with conflicts, and using verbal and non-verbal communication. The third critical juncture analyses consensus, how to accomplish this task addressing moral, cultural and religious issues. Critical juncture number four discusses comfort care including spiritual practices and therapeutic relationships. The fifth critical juncture involves family care and nurses' role in providing cultural competencies and examples of family focused interventions to assist this population with the grieving process. The sixth critical juncture looks at various aspects of end of life care and assuring a good death. The final critical juncture proposes post intensive care follow up and using family support groups as a tool for coping.

Conclusions

This work incorporates scientific rational into critical junctures to create an end of life care bundle.

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CHAPTER 1 INTEGRATIVE SUMMARY

My professional journey started as a bedside ICU nurse caring for patients suffering from multi-organ failure following physician orders for administering IV Adrenaline 50mg/hr and Noreadrenaline 64mg/hr. I had the sense that something was not right nor ethical in this scenario. I set on a journey to find the inotropic medication dose which was the maximum dose one could administer to a patient and still expect survival. This study evolved into the publication 'Characteristics of patients receiving vasopressors' (Benbenishty et al 2010). Although this paper was published in 2010, I initiated the research in 1999. The research took 3 years to complete and 7 years to realize publication.

This study progressed into the comprehension that recognizing when a patient stopped responding to life sustaining therapies and a new plan of action or treatment goals was needed, would become the next leg of my journey. In 1999 partnering with Professor Charles Sprung we initiated the ETHICUS study which not only enlightened us on different ICU cultures, but also opened additional avenues of investigation regarding end of life practices and nurse involvement. The first ETHICUS paper was published in 2003, and I published the sub analysis regarding nurse involvement in end of life care in 2006 (Benbenishty et al 2006).

Simultaneously using the ESICM platform, I continued searching into the many pathways of transition of care period leading me to investigate 'differences in European critical care nursing practice: a pilot study' (Benbenishty et al 2005). Perhaps nurses in different countries could enlighten, enrich and provide other perspectives of their practice. Following the ETHICUS study was the ETHICATT study, evaluating attitudes of Europeans regarding end-of-life decisions. Religion and religiosity were one of the factors analyzed and published from this study (Bulow et al 2012). Are there consequences on ICU teams' diligence, hard quality work and dedication during these trying crisis situations? This question led me to investigate moral distress and team conflicts (Ganz et al 2013).

I searched for biological explanations leading to the publication 'targeting patients' physiological and psychological outcomes' (Papathanassoglou et al 2015). The next years led my focus to exploring specific practices and competencies during

the transition from curative interventions to end of life care. Cultural, spiritual and communication competences were investigated with a variety of international collaborators. (Benbenishty 2014; Benbenishty & Biswas 2015; Benbenishty & Hannink 2015; Hartog & Benbenishty 2015). We created a multi-national team to investigate if the Palliative Quality Measures developed by Judith Nelson (Nelson et al, 2006) are applicable to cultures outside the United States. We observed nurse shift handovers in three countries and seven ICUs in order to identify how nurses practiced end of life care and if they handed over information regarding transitions from curative interventions to end of life discussions (Ganz et al, 2015). This paper led the team to investigate ICU nurses' perceptions of factors defining a good death (Endacott et al, 2016). Once these perceptions were revealed, I commenced exploring specific family, patient and ICU team practices and elements which are essential in this transition period. Nurses forming trusting therapeutic relationships from the patients' perspective (Benbenishty & Hannink 2017) was my next avenue of investigation.

My last years have been spent on implementing a family support group intervention to discover if we can alleviate some family distress and despair during the devastating crisis of ICU (Benbenishty 2015; Kirshbaum-Moriah et al, 2018). My journey has taken me to explore a wide perspective of caring for patients and families during life and death and our attempts to smooth the traumatic transitions that occur during this time. Using my published works together with other established evidence in the field of ICU transitions, the next stages of relevant explorations can be investigated.

1.0 Introduction

The integrative summary starts with background related to the nature of critical illness and critical care, the notion of crisis and uncertainty. The place of person and family-centred care for critically ill patients is explored and finally the goal of restoring stability to failing organs, disordered emotions and disrupted family dynamics is emphasised. The aim and objectives of the thesis are then presented in section 1.2 and two streams of work – studies designed to fill some of the evidence gaps for each objectives and studies specifically related to end of life care – are depicted. The body of work presented in the thesis comprises 16 papers, presented in 4 parts. A synopsis of the four parts is provided and the contribution of each part to the overall body of work is outlined in section 1.3. In order to set the scene a narrative review was conducted; this is presented at section 1.4 followed by comparison of relevant worldwide recommendations, section 1.5 and then an emerging theoretical framework at section 1.6. Finally, the evidence from the 16 papers and the narrative review is integrated into a proposed care bundle for end of life care in ICU. The next stage of my clinical academic journey will involve the testing of the newly developed end of life care bundle in ICU settings.

1.1 Background

The nature of critical illness and critical care

Unlike other specialties of medicine defined by organ system, disease process, or procedure, critical care has always been challenged to establish its identity (Adhikari et al, 2010). Traditional definitions of critical care focus on medical care for patients whose illness requires close, constant watch by a team of specially trained caregivers. Most critical care¹ takes place in an intensive care unit (ICU). As defined by the Society for Critical Care Medicine, intensive care units provide specialised care with equipment to treat the critically ill patient (Society of Critical Care Medicine, 2019). In the 21st century, high tech advances and new medications have, on the one hand, given society the ability to increase longevity of chronological age, but at the same time have increased the proportion of the population who are elderly or managing chronic disease from an early age. Today we face a population with multifaceted disease processes, severities of organ dysfunction, and risk of mortality, which we had not previously met.

Critically ill patients can generally be categorized into three types (Johnson et al, 2016):

1. Patients with acute organ failure; many whose outcome is unclear and may receive continuing intensive organ support.
2. Patients admitted after major surgery needing intense monitoring in the post-operative period to prevent and identify impending organ dysfunction.
3. Patients who are non-responsive to maximal intensive care therapy, receiving end-of-life care.

A multi-disciplinary team including nurses and physicians, respiratory therapists, physical and occupational therapists, dieticians, bio-technicians, pharmacists, nutritionists, and social workers provide intensive care. The daily routine in ICUs includes many varied proficiencies. The multi-disciplinary team must concurrently assess physiological/pathological organ function signs, resuscitate, diagnose, and

1. The terms 'critical care' and 'intensive care' are used interchangeably in the literature; intensive care tends to refer to the setting in which the critically ill patient is usually managed. The use of these terms in the thesis will be explained thoroughly.

provide state-of-the-art care for critically ill patients' rapidly deteriorating but possibly reversible path towards organ failure and death. There are current guidelines published by the Faculty of Intensive Care Medicine providing recommendations for practice, policy, education and research in the area of end of life care in critically ill adult patients (Faculty of Intensive Care Medicine, 2019). These recommendations provide a framework for improving education, communication, and involvement of policy-makers and national healthcare stakeholder organizations. Nurses and physicians' greatest challenge is to confront decisions regarding appropriate prolongation of life-supporting therapies for patients whose death has been delayed, but chances of regaining a meaningful survival is poor. The notion of crisis runs throughout all practices, professionals, and all categories of ICU patients and their families. Life threatening critical illness may cause multi-system breakdowns in which body organs and systems depart from known failure paths and 'behave' in seemingly erratic ways, jumping from one system to another, tending to generate a deeply felt sense of crisis.

Person and family-centred-care

Current guidelines emphasize that family support is a quality indicator and identified by patients and family members as an important part of ICU care (Davidson et al, 2017; Kon et al, 2016). Patients and families have identified important interventions, which improve care during their ICU stay (Bramley et al, 2014; Kirshbaum-Moriah et al, 2018). Patients and families report a paradigm of person-centred-care that stresses the uniqueness of each individual and the necessity to respect distinct histories, values, and preferences (White et al, 2007).

Nurses regularly assess the ways in which families and patients cope with and understand what is going on in ICU. For optimal satisfaction, they should be informed as much as possible (Davidson et al, 2017) should. Efforts to improve quality should focus on domains and processes that are most valued by critically ill patients and their families (Nelson et al, 2010 page 11).

Families and patients express confusion and dissatisfaction with physicians' use of medical terms. In a study exploring patient and family definitions of high-quality palliative care in ICU, patients and families stressed awareness of personhood, defined

in the literature as the belief that “each person is unique, has inherent values, and is worthy of respect and honour regardless of disease or disability” (Nelson et al, 2010 page 12). Other researchers perceive it as a measure of excellence for ICU teams to care for patients with the same attitude and concern they would give to their own family member (Benbenishty & Hannink, 2017; Peigne et al, 2011). Nursing interventions must aim to support patients and family members with a focus on religious, cultural, ethical and conflict management skills to provide holistic care in the ICU environment.

Restoring stability

In ICU patients, hemodynamic systems are at disorder in nature; from turbulence in fluids, the erratic flows of vascular systems to the arrhythmic writhing of the heart. At their cellular, organ, total body, emotional, mental, familial and social levels patients admitted to the ICU lose the systematic routine of their lives and face chaotic complexities. Stability is an emergent property of complex organ systems that characterizes complex adaptive processes and it is essential to living organisms (Papathanassoglou et al, 2008).

Nurses are the clinicians closest to the patients in daily monitoring, assessing, intervening with treatments and evaluating the outcomes. They evaluate all the physiological abnormalities, emotional instabilities (delirium, delusions, non-sleep rhythms, and agitation) as well as spiritual assessment regarding religious beliefs, cultural rituals and family relationships. In addition to their work with the patients, they believe that family and social relationships are an integral element in wellbeing outcomes (Kon et al, 2016). Therefore, ICU nurses target their interventions to optimize patient homeostasis as well as family support and stability. There is a need to examine the variables nurses use when assessing life threatening and end-of-life situations whether from the patients, the ICU team or family perspectives. During routine care delivery, nurses collect data from numerous sources, use critical thinking and emotional intelligence to mitigate and advocate for patient and family best interests. In the literature, there are a multitude of scientific findings demonstrating nursing assessment, interventions and evaluations but no studies examined the

integration of the multifaceted scope of nursing care during life threatening situations throughout the transition from ICU treatment to the care at the end-of-life.

1.2 Aim of thesis

This thesis will examine the context, purpose, and significance of life threatening and end-of-life situations in ICU and demonstrate the integral work of nurses in calming, organizing and making sense of ICU life and death conditions.

The objectives of this thesis are:

- To explore nursing identification and assessment of life threatening and end-of-life situations which ICU patients face
(papers: 1, 2, 3, 4)
- To identify cultural, religious, ethical and spiritual competencies nurses need to deal with patients' and family's' instability and end-of-life crisis
(papers: 5, 6, 7, 8, 9)
- To examine nurse communication skills in critical situations
(papers: 10, 11, 12, 13, 14)
- To investigate nursing interventions promoting family members' coping
(papers: 15, 16)

In this thesis, the contribution of the body of work to our current understanding is provided in two streams of work:

1. Studies providing generic evidence to address each objective
2. Studies examining specific end of life care issues related to each objective

Figure 1 illustrates how these two streams of work address the study objectives.

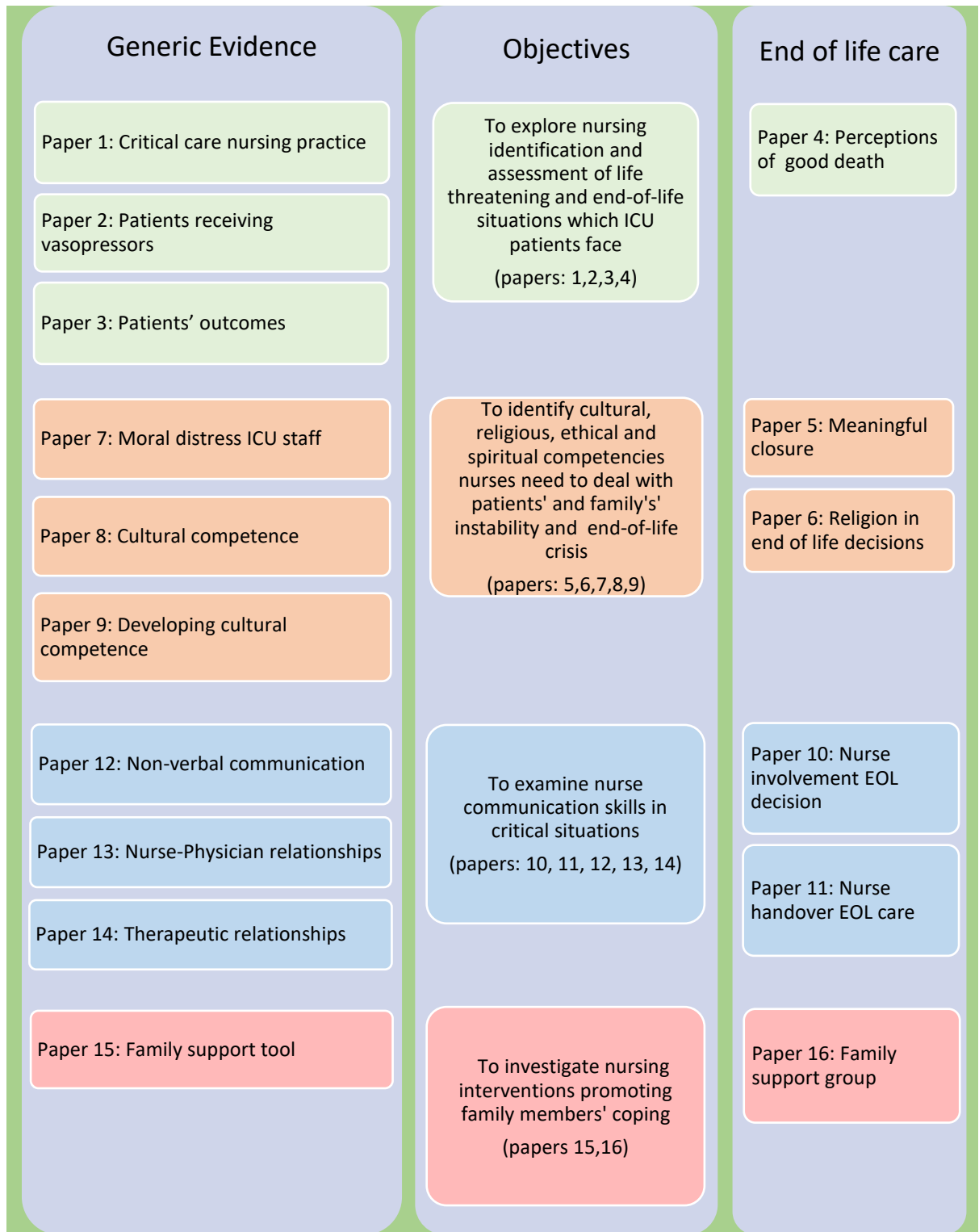


Figure 1. Links between the study objectives and thesis papers related to evidence gaps and end of life

1.3 Thesis structure

The papers comprising the thesis are presented in four parts representing stages during transition from curative interventions to end of life care and corresponding to the four study objectives. The first stage includes the identification of disease non-responsiveness to maximal interventions. The second stage reflects the staff skills, experience and knowledge needed to deliver appropriate end of life care. The third stage demonstrates communication styles and techniques in providing suitable treatment. The fourth stage presents a research intervention fulfilling family needs during intensive care hospitalization and crisis

PART A: Nursing practice in ICU life threatening situations

The four papers comprising Part A consists of research related to skills needed to ensure optimal ICU nursing care in life threatening situations.

This part includes the following papers:

- 1: Differences in European critical care nursing practice: a pilot study (Benbenishty et al, 2005)
- 2: Characteristics of patients receiving vasopressors (Benbenishty et al, 2011)
- 3: Perceptions of a good death: a qualitative study in intensive care units in England and Israel (Endacott et al, 2016)
- 4: Research advances in critical care: Targeting patients' physiological and psychological outcomes (Papathanassoglou et al, 2015)

PART B: Cultural, religious, ethical and spiritual competencies of nurses in ICU

The five papers comprising Part B are related to the multi-variable competencies' nurses need in order to deliver holistic nursing care. This work attempts to uncover and examine the multi-faceted critical thinking and emotional intelligence expressed and used by nurses to deliver excellent care to the critically ill patient and family and end-of-life care.

This part includes the following papers:

- 5: A meaningful closure (Benbenishty 2014)

6: Are religion and religiosity important to end-of-life decisions and patient autonomy in the ICU? The Ethicatt study (Bulow et al, 2012)

7: Moral distress and structural empowerment among a national sample of Israeli intensive care nurses (Ganz et al, 2013)

8: Cultural competence of ICU nurses in critical care: Case studies in the ICU (Benbenishty & Biswas, 2015)

9: Developing cultural competence in clinical practice (Benbenishty & Biswas, 2015)

PART C: Nurse Communication skills in critical situations

The five papers comprising this part describe issues related to communication skills of nurses in critical situations. Communication has been identified as one of the most important competencies needed in end-of-life care. Communication includes a wide range of skills, from active listening, comprehension, nonverbal to expression of empathy and hope when confronted with death. This part sheds light on a few aspects of communication in the ICU environment.

Part C includes the following papers

10: Nurse involvement in end-of-life decision making: the ETHICUS Study (Benbenishty et al, 2006)

11: The quality of intensive care unit nurse handover related to end-of-life: A descriptive comparative international study (Ganz et al, 2015)

12: Non-verbal communication to restore patient-provider trust (Benbenishty & Hannink, 2015)

13: Understanding nurse-physician conflicts in ICU (Hartog & Benbenishty, 2015)

14: Patient perspectives on the influence of practice of nurses forming therapeutic relationships (Benbenishty & Hannink, 2017).

PART D: Nursing interventions promoting family members' coping

The two papers in Part D present the initial work related to family support in ICU. This body of work shows new possibilities for nurses to implement change in their support of ICU families. Although the family support group intervention is not explicitly directed to include families during end of life process, all families are invited to participate. Some families participating in the support group did lose their loved one

during their ICU stay. This intervention can be used for all ICU families during the transition phase from curative interventions to end of life care as well as those families surviving ICU experience.

Part D includes the following papers:

15: Family support group: a tool for nurses (Benbenishty 2015)

16: Family members' experience of intensive care unit support group: qualitative analysis of intervention (Kirshbaum-Moriah, Harel & Benbenishty, 2018)

1.4 Narrative review: The transition of decision-making goals of care to end of life in intensive care

To set the scene for the evidence to be presented in this thesis, a narrative review was undertaken. This clarified the range of topics investigated and associations between, firstly, the variables important in transitions from curative treatments to end-of-life interventions and, secondly, involvement of and relationships between professionals, patients and families.

Introduction

This review explores the specific time of transition in goals of care in critical care settings. Typically, patients are admitted to intensive care with the intent to curative goals of care and hopes of recovery. A patient can quickly deteriorate and the transition from critical illness to the point of futility and the processes of dying may be rapid and difficult to manage (Pattison 2006). One of the greatest challenges across health care teams continues to be consensus and acceptance of the concept of futility of treatment and the concept of dying (Coombs et al, 2012).

Critical care teams identify that decision-making regarding goals of care and aggressiveness of curative interventions are sensitive to multiple elements, fluctuating patient response to treatments, variability of patients' condition, preferences of families that may change over time, and perceptions and opinions of other treating physicians and nurses. In the normal course of critical care, recognition that curative interventions and if goals of treatment are not effective should stimulate ICU professionals to explore other approaches or additional diagnostic testing.

Rationale for review

There is a need to focus on transition from curative interventions to end of life care (EOLC), rather than end of life care itself so that effective and timely decision making underpins the care of the 20% of intensive care patients who die in these settings each year (Coombs et al, 2012). In intensive care settings, the transition from curative interventions to end of life (EOL) is a complex process with many critical junctions and turning points at which decisions must be made regarding patient management. A phased transition, or simultaneous care approach, recognizes that treatment goals evolve and maybe particularly relevant for patients with non-cancer conditions, where

the trajectory of decline is both unpredictable and highly variable. Although EOL recommendations for critically ill patients exist (Truog et al, 2008), development of a clear pathway for end of life care has been described as complex (Ramasamay et al, 2015). Consequently, and despite the current evidence, there is no clear summative overview of the existing literature related to the transition into EOLC for adult ICU patients. Therefore, the objective is to conduct a narrative review of evidence regarding transitions from curative treatment to EOLC for adult patients in ICUs and to identify gaps in the evidence underpinning the transition to the delivery of EOLC.

Method

A narrative review summarizes different primary studies from which conclusions may be drawn into an integrated interpretation (Kirkevold 1997, Mays et al, 2005). A narrative review methodology was chosen to synthesize the observational work and limited research on the topic.

The mnemonic PCC (population, concept and context) was used in order to formulate the review question (Archibald et al, 2016). The Population is ICU patients, families, physicians and nurses involved in the transition period of deciding goals of care from curative interventions to EOLC. The Concept is to define and identify factors comprising the transition in goals of care. The Context is ICU environment and the relationship between players involved in decision making during transition in goals of care. The review question is: What are the factors to be considered during the transition from cure to end of life oriented care in intensive care and relationships between the key players: patients, families, nurses and physicians?

An initial search was performed to identify relevant articles to define relevant keywords to inform a definitive search strategy. MEDLINE and EMBASE (no time boundaries were set) were searched for studies including all languages using the search terms: Transitional care (Medical Subject headings MeSH) OR transition AND clinical decision-making (MeSH) OR goals of care AND palliative care (MeSH) OR terminal care OR end-of-life care AND critical care OR intensive care (Title/Abstract).

The authors reviewed the search results and only articles relevant to transition in decision-making goals of care to end of life care in ICU were included. The included articles were then searched for relevant references. Inclusion criteria were

intentionally broad and included any article in any language discussing the process of transition in goals of care in decision-making in adult critical care. Conference abstracts, opinion papers were excluded. Articles related to transition from acute to chronic illness were also excluded as well as articles related to pediatric and neonatal intensive care. Each article was reviewed, and content was analyzed.

Two reviewers carefully read the articles and extracted any relevant terms or descriptors that were used to define factors to be considered during transition from curative goals of care to end of life care and decision-making in intensive care. Where the reviewers did not match in the findings analyzed, they went back to the original article and worked through until consensus was reached. These findings or descriptors of the transition period were then grouped together into broader categories. The second step involved developing a preliminary synthesis of the findings of the included articles using narrative analysis by translating the data to identify areas in common between the articles. The two reviewers carefully read the articles and extracted any relevant terms used to explore transitions in decision- making goals of care to end of life care. Where the reviewers did not match in the terms selected from the article, they went back to the original article and worked through until consensus was reached. These 'findings' or descriptors of the transition period were then grouped together into broader categories. From the level of 'category', the two reviewers used the seminal text results with the findings from the wider literature review to create some broader themes and sub-themes. In this way, a synthesis of transitions in decision- making goals of care to end of life care terms and phrases was carried out across the 27 published papers.

Step three involved exploring relationships within and between articles by systematically exploring the differences between the articles. Steps two and three occurred concurrently and involved identifying differences and similarities between the findings of the included studies and synthesized themes.

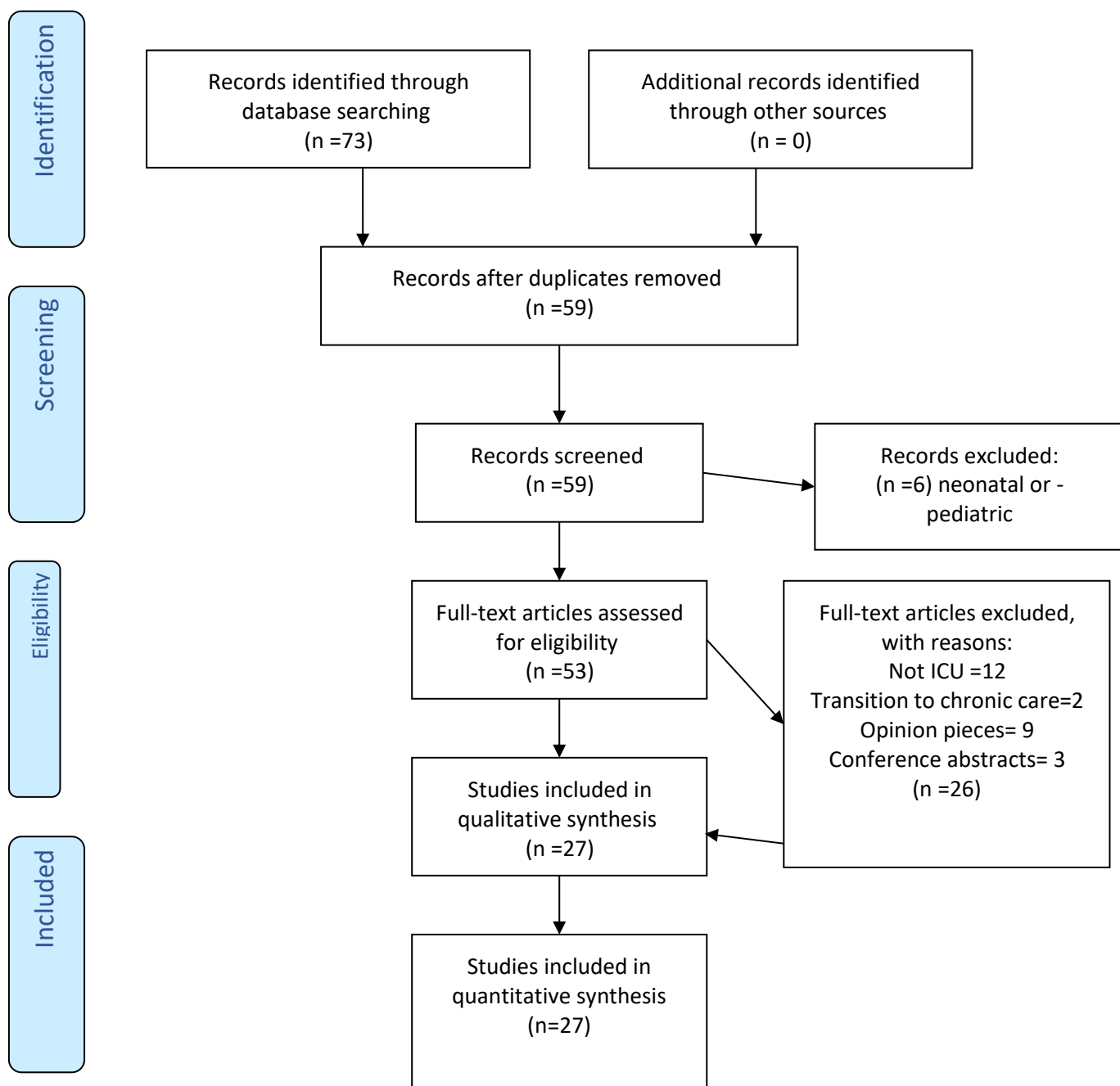


Figure 2: Flow chart of the literature selection process.

Results

The review strategy resulted in 27 papers (Figure 2). The narrative synthesis comprised:

- i. Eight qualitative research studies (Adams et al, 2013; Badger 2005; Brooks et al, 2016; Brooks et al, 2017; Coombs et al, 2012; Graftieaux et al, 2014; Robichaux et al, 2006; Pattison 2006). These eight articles investigated nurses and physicians using a qualitative focus group methodology and individual interviews analyzing perceptions and experiences of transitions to end of life care, and two papers report the implementation of a pre/post-educational intervention quantifying the effect of communication and educational interventions on ICU teams. The three articles investigating nurses were all qualitative in design looking at expert nurse and conflict management, barriers and facilitating factors in the transition period, and nurse's perception of contributing factors to family understanding of patients' end of life process.
- ii. Seven papers reporting the retrospective analysis of medical files (Barwise et al, 2018; Chavez et al, 2018; Kavic et al, 2003; Koff et al, 2017; Miller et al, 2015; Morgan et al, 2014; Oud 2017); exploring specific patient populations, oncology, lacking language proficiency, patients with dementia, disclosing decision-making processes, and case studies.
- iii. Six review papers (Biskup et al, 2017; Coombs et al, 2010; Harvey et al, 2018; Knies et al, 2016; Leung et al, 2017; Levin et al, 2010); These reviews looked at specific ICU patient populations (oncology and liver transplant), conceptual and discourse analysis, performance measurements, ICU end of life recommendations and best evidence, and decision-making transitions.
- iv. Four quantitative surveys (Daly et al, 2018; Lamba et al, 2012; Piers et al, 2011; Wessman et al, 2017)
- v. Two randomized controlled trials (Curtis et al, 2016; White et al, 2018): The two randomized controlled trials exploring decision-making interventions on family long-term outcomes. Family and physician quantitative articles looked at influence of family response on physician views, in comparison to the consistent effect of survival probabilities, barriers to incorporation of values in treatment decisions and a pre/post-palliative care team interventional study.

Narrative Synthesis of the 27 papers resulted in eight themes: 1. Communication; 2. Goals of care; 3. Family; 4. Quality of life; 5. Ambiguity; 6. Balance between harm and burden; 7. Documentation; 8. Education and training.

Theme 1- COMMUNICATION

Communication was a common theme in 24 of the included studies and many different communication strategies were explored (Table 1). There were three sub-themes: Decision-making, Communication barriers and Consensus.

Five studies were interventional in design. Three studies were pre/post educational interventions educating staff regarding issues of palliative care (Lamba et al, 2012), ICU based goals of care/end of life (GOC/EOL)-focused programs providing a multidisciplinary communication approach for families (Wessman et al, 2017) and educating staff on the Belgian laws on patients' rights and advanced care planning (Piers et al, 2011). The findings of these interventions showed positive results on staff knowledge; however no evidence was documented that the interventions had an impact on quality of patients' EOLC. Of these three studies, two measured the effect of the intervention on staff, and were not patient or family focused. Two of the five interventional studies used a randomized controlled trial design measuring the effect of interventions on families. White (2018) and Curtis (2016) developed and implemented communication interventions. Curtis (2016) researched the impact of communication facilitators and White (2018) examined an inter-professional team communication intervention (Curtis et al, 2016; White et al, 2018).

Decision-making

One of the communication outcome measures found in White (2018) study was improved quality of decision-making. Curtis (2016) found that family members have long-term significant burden of psychological symptoms because of their role in decision making in ICU (Curtis et al, 2016; White et al, 2018). Brooks (2017) found that, although nurses and physicians accepted the value of incorporating different people's views in shared decision-making, in actual practice, this was a difficult goal and it is unfair to present such challenging decisions to the family to make (Brooks et al, 2017). A Swiss study investigated oncology patients in ICU and concluded that a consensus decision should be based on a general specialists' opinion as well as according to the dynamics of organ failure. If the continued organ failure does not indicate a clinical

improvement, a de-escalation of therapy should take place while the quality of life, patient's wish and family opinion should also be taken into consideration (Biskup et al, 2017). Millers' 2015 review revealed how critical care teams sought early joint decision-making with consulting medical teams when there was doubt over the possibility of critical illness recovery. This planning meant that some patients transferred out of the unit and received EOLC on the ward. Poor critical illness related outcomes and cancer prognosis made it straightforward to reach consensus and rationalize decisions (Miller et al, 2015).

Communication barriers

Several papers identified barriers in communication regarding transitions of care. Koffs' (2017) study exploring cancer patients admitted to ICU discussed the misunderstandings about transitions in care (Koff et al, 2017). Miller (2015) found that only 30% of end of life patients were offered spiritual, psychological and welfare support (Miller et al, 2015). Piers (2011) found that only 17% of patient population was referred to palliative care service, because teams did not communicate this option (Piers et al, 2011). Oud's 2017 study found time gaps in communication (Oud 2017). Badger's (2005) study found that nurses felt transition points between cure and comfort-oriented care was unclear. Misunderstanding illness by family, family discord, and shifting medical decisions made transitions difficult (Badger et al, 2005). Brooks (2016) found barriers including conflicts between ICU physicians and external medical teams, the availability of education and training, and environmental limitations (Brooks et al, 2016).

Consensus

Several studies looked at the relationship between specific ICU populations and transitions of care. Lamba (2012) study exploring liver transplant patients found positive interdisciplinary communication interventions with physicians and families resulted in earlier consensus around goals of care for dying transplant patients. Early integration of palliative care alongside disease-directed curative care was accomplished in the ICU without change in mortality improving end-of-life care practice in liver transplant patients (Lamba et al, 2012).

Other populations in this review included patients suffering from: traumatic brain injury, chronic illnesses, dementia, oncology/hematology and had limited proficiency

in English. Many articles identify that the primary problem in defining the transition phase of care is because the terminal stage of illness is poorly defined and extreme difficulties exist in providing an accurate prognosis (Harvey et al, 2018; Barwise et al, 2018; Leung et al, 2017; Lamba et al, 2012; Oud 2017; Chavez et al, 2018; Biskup et al, 2017; Miller et al, 2015).

Theme 2- GOALS OF CARE

This review identified 19 studies comprising the theme goals of care. Establishing goals of care is a dynamic process, which needs reviewing frequently (at least once a day). The two sub-themes were discord among treating physicians and discord between nurses and physicians.

Discord among treating physicians

One of the most common factors influencing goals of care described in the included articles related to the subspecialties of physicians caring for patients in ICU; Oncologists compared to ICU physicians and surgeons compared to ICU teams (Chavez et al, 2018; Biskup et al, 2017; Piers et al, 2011; Koff et al, 2017). Most articles found that while the ICU physicians were willing to provide an "ICU trial" for oncology/hematology patients, they were faced with challenging the referring oncologist with transitioning decision-making before the oncologist was ready. When deciding goals of care, frequent tense situations and conflicts occurred when deciding "what was best for the patients versus best interest for the family (Leung et al, 2017; Miller et al, 2015).

Discord between nurses and physicians

Nurses reported difficulties in providing a good death, suffering from moral distress, severe conflicts in the ICU environment and avoiding family encounters as a result of misunderstandings and uncertainty (Leung et al, 2017; Robichaux et al, 2006; Badger et al, 2005; Adams et al, 2013; Miller et al, 2015; Coombs et al, 2012).

Pattison's (2006) discourse analysis of provision of end-of-life care in key UK critical care documents recommended that nurses remember core caring skills and promote comfort care when the goals of critical care become futile (Pattison 2006). Coombs (2012) emphasized that nurses managing the transitional phase of care are overwhelmed with tension. Furthermore, Coombs concluded:

".... there is currently limited guidance on how to manage transitioning from cure to end of life. Until such approaches are developed and adopted, intra and interdisciplinary tensions arising from diverse professional motivations for cure within end of life care decision" (Coombs et al, 2012, pp 526).

Theme 3- AMBIGUITY

Seven studies were included in the theme ambiguity. There were four sub-themes:

Uncertainty regarding treatment continuity, family disharmony, diagnostic indecisiveness, conflicting values.

Uncertainty regarding treatment continuity

Two studies that analyzed retrospective patient files found variable practices, and staggered approaches to transitions of care (Koff et al, 2017; Miller et al, 2015). Practices that involved the sequential withholding or withdrawing of life-sustaining interventions, while often continuing others. This practice may reflect the initial step in the negotiation process of redirecting the goals of a dying patient's care from curative to EOLC, particularly in situations where families demonstrate conflicts in EOL decision-making (Morgan et al, 2014; Chavez et al, 2018).

Family disharmony

Decision making responsibility referred to relatives who may be more hesitant to advocate reversals and limitations than the patient may themselves, if not previously addressed in documents like living wills (Kavic et al, 2003). Alternative processes to represent patient preferences rather than family member's best guesses are an important area of ambiguity (Wessman et al, 2017).

Diagnostic indecisiveness

In Coombs (2012) qualitative study, a key phrase often used by health care staff at transition stage was that "treatment was futile" and that the patient was dying. In some situations, this was clear to all and very evident whilst at other times patient outcome was less clear and difficult to predict. Making a diagnosis of dying was not only informed by objective clinical data and decision-making variables but also using individual viewpoints, beliefs and experiences of medical staff were also factors that made identification of the transition point from intervention to end of life care, problematic (Coombs et al, 2012). Robichaux and colleagues (2006) noted that five

participants expressed the anger, guilt, and despair that commonly occur when one feels morally responsible for the best interests of the patient, but are unable to change what is happening; the unpredictable nature of the dying process in the ICU creates a “vanishing line” between life and death. This inability to identify a patient as terminal often results in adherence to curative regimens almost to the moment of the patient’s death. The expert critical care nurses in this study were often the first to acknowledge recognition of this equivocal transition from possible recovery to an understanding that further efforts would be futile. They reported that the use of phrases and ambiguous words such as “treatment” contributes to medical activism and that such words may have a more positive meaning for patients because the words imply that “something can be done about it.” Medical activism and false hope also make it more difficult for patients and their families to accept a patient’s imminent death, obstruct saying farewell, and cause delays in making final arrangements (Robichaux et al, 2006).

Conflicting values

A systematic review by Levin (2010) reflected the blurred boundary between curative and EOL goals of care being vulnerable to misperception and disagreement conflicting values, culture, religion and prognostic challenges can amplify emotions (Levin et al, 2010). Terms like stuttering withdrawal of life-extending treatment, because of avoidant end-of-life communication, added to the sense of ambiguity (Levin et al, 2010).

A qualitative study in Canada analyzing 16 ICU nurses' experiences found that they felt tension in knowing patients’ poor prognosis and anticipation of their death, while at the same time wanting to alleviate family suffering. Participants anticipated that patients would experience a protracted dying and expressed distress at foreseeing the terminal trajectory and the apparent inappropriateness of cure-oriented treatment. By actively concealing knowledge of the patients’ anticipated dying, nurses were preserving hope: organizational or unit protocols reinforced the tendency to use recovery-oriented interventions versus protecting the patient from unnecessary painful procedures (Badger et al, 2005). In the critical discourse analysis of four key UK critical care documents, Pattison (2006) found a certain degree of ambiguity in the reluctance to discuss the implications of caring for patients at the

end-of-life in critical care through the use of the terms 'appropriate' and 'difficult' or 'difficulty'. 'Appropriate' and 'difficulty' are subject to individual interpretation (Pattison 2006).

Theme 4- FAMILY

Thirteen studies included family as the theme. There were four sub-themes: Family involvement, family contribution in goals of care transitions, Family outcomes as a measure of end-of-life care intensity and ICU team-family synergy.

Family involvement

Most studies reported the importance of family involvement in transition discussions. This involvement included establishing patients' values and preferences (Robichaux et al, 2006; Morgan et al, 2014; Coombs et al, 2012), establishing families' expectations (Harvey et al, 2018; Brooks et al, 2016; Leung et al, 2018), assisting families in coming to terms with the implications of their involvement in treatment decisions (Chavez et al, 2018; Lamba et al, 2012), and managing the emotional family response (Leung et al, 2018).

Families contribution in discussions goals of care transitions

Kavic (2003) found that families initiated the end of life discussion, which led to transition of care, while Badger found family indecisiveness because of misunderstandings and family discord (Kavic et al, 2003; Badger et al, 2005). Conversely, asking families who had limited knowledge or understanding of the patients' illness to contribute in transition discussion led to extending life sustaining interventions, which prolonged patient suffering (Badger et al, 2005).

Family outcomes as a measure of end-of-life care intensity

Curtis 2016 and White 2018 qualified the effectiveness of their communication intervention and the intensity of end of life care by measuring the burden of psychological stress on relatives of ICU patients associated with having a critically ill family member 3- and 6-months post ICU discharge (Curtis et al, 2016; White et al, 2018).

ICU team- family synergy

Adams 2013 study found that when the ICU team recognize an impending death and guide the family's acceptance of this outcome, the family is able to navigate their own perspective of the transition from curative to end of life care. Use of Adaptive Leadership techniques by the ICU team throughout the trajectory of an ICU stay will help family members develop a realistic understanding of the prognosis (Adams et al, 2013)

Theme 5- QUALITY OF LIFE/COMFORT

There were four sub-themes: Avoidance of futile treatments, Ensuring comfort care delivery, Palliative care consultation in ICU and Quality of life versus longevity.

Avoidance of futile treatments

Eight studies comprised this theme quality of life/comfort. A study described the French laws about treatment withdrawal allowing death to occur, that is, to avoid prolongation of the dying process by interventions that are futile, costly, and possibly degrading quality of life (Graftieaux et al, 2014). Leung and colleagues (2017) concluded that as a result of the poorly defined period of transition into terminal stage combined with the nursing effort to continually provide hope to families, reduced the possibilities of providing a good death. ICU teams were routinely expected to provide life-sustaining treatments to patients with chronic critical illness, even though palliation and end-of-life care were available and in the best interest of patients' diminishing quality of life (Leung et al, 2017).

Ensuring comfort care delivery

Wessman (2017) developed an intervention, which included standardized goals of care and a comfort care computer order set was created to help direct physicians prescribing appropriate comfort care interventions. This order set focused on discontinuing any unnecessary painful interventions and eliminating invasive monitoring. It also focused on the appropriate analgesics and sedatives for EOLC (Wessman et al, 2017).

Palliative care Consultation in ICU

Biskup (2017) found that palliative care services are probably underutilized in the ICU and yet often prompt advance directives. Compromise of a patient's quality of life, permanent invalidity, and non-beneficial utilization of limited medical

resources were reasons to disfavor intensive therapy for oncological patients (Biskup et al, 2017).

Quality of life versus longevity

Daly (2018) summarizes that priorities of what each physician believed was most important in making decisions (quality of life versus length of life) had no significant influence at any time point. In addition, this paper demonstrated the persistent power of culture that prioritizes length of life over quality (Daly et al, 2018).

Theme 6- BALANCING HARM AND BURDEN

There were three sub-themes: Harmony between intensive interventions and burden of treatments, Equilibrium between paternalism and total family responsibility in decision-making and Balance of intensive care and end of life care in critical care environment.

Harmony between intensive interventions and burden of treatments

The four studies included in this theme balancing harm and burden, concluded: in transition situations when a rapid and significant escalation in therapy is required to maintain physiological stability, which is valid when an expected benefit outweighs risks and harms, the responsible consultant should review the relative harms and burdens of continued intensive care regularly (Harvey et al, 2018; Chavez et al, 2018; Levin et al, 2010; Pattison 2006). Estimating patient risks for changing preferences shifts the balance of risks, benefits, and harms that are acceptable to patients when proceeding with trials of potentially burdensome, but life sustaining, treatments (Harvey et al, 2018; Chavez et al, 2018). When both health professionals and the public systematically overestimate the efficacy of life prolonging treatments, critically ill patients may receive burdensome high intensity treatments that do not effectively improve their quality or quantity of life (Harvey et al, 2018; Chavez et al, 2018).

Equilibrium between paternalism and total family responsibility in decision-making

Levin (2010) found that after discussing end-of-life care options, a clear physician recommendation should guide the family, avoiding both the extremes of paternalism and “dumping” the decision on the family. Another ethical principle is making decisions in the patient's best interests. This is determined by considering the patient's condition, prognosis, the benefits/burdens of treatment options and the

patient's prior views. Thus, the decision-making burden is truly shared. This avoids the misperception that, e.g., “we killed grandma” (Levin et al, 2010 pp 439).

Balance of intensive care and end of life care in critical care environment

Pattison (2006) reviewed the in 1999 published Audit Commission’s report, ‘Critical to Success’ suggested that discharge should be considered in the event of the patient ‘no longer benefiting’ from critical care and also when patients or families wished for transfer elsewhere, where ‘palliative care can be provided’. Implicit within the documents is the suggestion that end of life care cannot be provided in critical care. This illustrates a dilemma of discharge at EOL, Comprehensive Critical Care DoH document summarizes primarily about patients who would not benefit from admission and overlooks the considerable number whose condition deteriorates to the point of dying after admission. Comprehensive Critical Care (DoH, 2000) refers to the 1996 DoH document for guidelines on discharge good death and good EOL care need not happen only outside critical care (Pattison 2006).

Theme 7- DOCUMENTATION

There were two sub themes: Communication template and order, and Do Not Resuscitate (DNR) documentation. Three studies contained the theme documentation.

Communication template and order

Wessman 2017 designed an intervention which included implementation of communication templates for physicians and nurses to help guide conversations with patients and families. A documented set order of comfort care practices and a patient–family pamphlet was created to provide basic education for patients and family members facing transition decisions (Wessman et al, 2017). A study from the USA demonstrated measures reflecting quality of end-of-life care included documented information-sharing session between the practitioner and patient or proxy (Koff et al, 2017).

DNR documentation

A Belgium study found that a hospital-wide information campaign improved the documentation of participation in and the rationale for Do-Not-Resuscitate (DNR) decisions. The outcome measure is the presence of a DNR order at the time of death

on non-ICU wards, because these decisions could be a potential turning point in transforming the goals of care from a curative to a more end of life approach (Piers et al, 2011). This study found wide variations between hospital departments and ICUs in end of life decision documentation. Although the completion of the written DNR forms improved significantly post intervention by introducing a new DNR form; however, there was no improvement in the actual pro-active end of life behavior of physicians.

Theme 8- EDUCATION AND TRAINING

Three sub themes comprised this theme: Informing staff on national law and new forms, ICU end of life care training, and insufficient education and training.

Four studies discussed education and training.

Informing staff on national law and new forms

A Belgium hospital-wide intervention consisting in informing hospital staff on the law on Patient's Rights, the introduction of a new DNR form, tips on open communication where, emphasis was on the importance of motivating and communicating the DNR decision. Post intervention period resulted in physicians better documented who participated in DNR decisions, and the motivation for these decisions. However, the study found that the intervention did not affect any of the predefined quality indicators (Piers et al, 2011).

ICU end of life care training

A USA Palliative Care education intervention to improve the quality of end-of-life care was integrated into standard ICU practice. The program incorporated educational and clinical aspects of palliative care (Lamba et al, 2012). Another United States study implemented formalized didactic sessions with physicians, nursing, and the health care team to improve education regarding goals of care in end of life issues. Innate empathy can provide a nice framework, but more formalized education and guidance assisted providers with their own emotional challenges as they face end of life stressful interactions (Wessman et al, 2017).

Insufficient education and training

An Australian 2016 qualitative study found that scarcity of education and training was one of the barriers nurses and physicians felt meant that they were unable to initiate end of life discussions (Brooks et al, 2016).

Discussion

This analysis presented a narrative review of the published literature on transition from curative interventions to end of life care in adult ICUs and to identify gaps in the evidence underpinning the delivery of end-of-life care. Relatively few publications relevant to transition were found, and most of these were observational studies, reviews, and qualitative interviews.

Nevertheless, the available evidence reflects the importance of identifying elements of and factors which impact on transition including aspects of communication, decision-making, goals of care, family involvement, ambiguity, balancing harm and burden, documentation, and education and training.

The literature describes significant variation in ICU practice during transition. The reasons are many including culture, legal and ethical practices, feelings of moral distress and the difficulties in accurately knowing if a patient will no longer respond to life saving curative interventions. Improving training and education in end-of-life care may reduce some of this practice variation and help to improve patient care. The transition from curative interventions to end of life care is perceived as an integration of values of families, patients, and ICU teams as well as the society in which we live.

Communication is one of the principle issues researched in the ICU literature regarding this transition period. Several communication strategies were explored with many outcome indicators measured. Because of the different strategies and various outcome measures, it is difficult to arrive at an overall recommendation. One fact was consistent in all articles, critical care clinicians need to be competent in team and family-centered end of life communication. They should be able to manage a family meeting to promote consensus and discuss the transition from curative to end of life goals of care, Allow Natural Death/ Do-Not-Resuscitate directives, withdrawal of life sustaining treatment and the dying process. Emerging evidence suggests that better EOL communication may impact on patient outcomes such as the quality of the death, bereavement, length of ICU stay and cost of end of life care (Levin et al, 2010). The

ability to reach consensus using shared decision-making are dominant components in communication strategies found in the majority of articles in this review (Curtis et al, 2016; White et al, 2018; Badger et al, 2005). Curtis et al (2016) and White et al (2018) randomized control studies attempted to implement a communication strategy with the objective to relieve family depression and depression. Neither of these strategies reached significant impact on relieving family depression. However, the interventions reduced ICU length of stay and allowed surrogates to transition a patient's treatment to comfort-focused care when doing so aligned with the patient's values (Curtis et al, 2016; White et al, 2018). The lack of significant findings most probably can be attributed to the inability to quantitatively ascertain the ways in which the intervention changed care processes surrounding family communication (White et al, 2018). In Curtis et al (2016) study, the lack of statistically significant findings might be attributed to the fact that the communication facilitators were external interventionists, sample size was below target, and many families were lost to follow-up. However, positive findings included the number of hospitals that participated in the quality improvement to enhance EOLC in the ICU, which might enhance the quality of palliative care in "usual care"(Curtis et al, 2016).

Defining goals of care throughout the transition process is a concept most articles discussed. Chavez 2018 found that patients transferred to the Intensive Care Unit from Hematology and Oncology services were more likely to have any DNR orders, while patients from Surgical, Cardiovascular and Cardiac Intensive Care Unit services were less likely. Decision variation is expected when different primary specialty teams reflect patients with different disease states (e.g. cancer), corresponding prognosis, and acceptable treatment goals (e.g. elective surgery). Clinicians and patients have different perspectives or abilities to recognize conditions amenable to intervention. For example, we may recognize metastatic cancer as an intractable terminable disease while believing there are always more interventions to salvage patients with cardiac and surgical problems. (Chavez et al, 2018). The best treatment scenario is when all invested parties agree on goals of care treatment and consensus is achieved. Perhaps the most important factor that enables nurses to move from cure to end of life-oriented care is developing a consensus about the direction

of medical treatment between staff, the patients' families, and the patients themselves (Adams et al, 2013; Badger et al, 2005).

The review found that transition junctures and deciding goals of care is the most problematic, and ambiguous stage in the end of life trajectory, with potential for conflict between medical teams (Coombs et al, 2012). This climate of conflict and ambiguity are additional factors affecting communication and one of the greatest challenges in ICU care.

Family members are central players in the transition period. Through these surrogate decision makers, we need to investigate patients' preferences, desires, reach consensus and explore to what extent the family members want to be involved in decision-making, another profound challenge in the transition period.

The complex practice ICU teams coordinate while caring for the transitioning patient, seeking and deciding what is the best for the patient, providing hope and bereavement towards family, at the same time feelings of ambiguity, uncertainty and moral distress.

Culture is a powerful influence regarding extent of family involvement in decision-making. American studies reflect that families are primary decision-makers in end of life care (Curtis et al, 2016; White et al, 2018). While multi-center European and Asian studies show a wide range of family participation in goals of care decisions (Sprung et al, 2003; Sprung et al, 2014; Yaguchi et al, 2005). Health care providers as well as the family members strive to promote the best quality of life and comfort to all patients (Daly et al, 2018). The critical balancing ICU teams do when weighing risks, benefits, and harms that are tolerable to patients when proceeding with burdensome, but life sustaining, treatments. At the same time, futile treatment is not in the patient's best interests. Clinicians should try to find the balance between clinical realism and family desires (Chavez et al, 2018).

Documenting outcomes of family/team conferences, changes in goals of care and do-not-resuscitate orders are considerably important in the delivery of consistent and humanistic end of life care (Koff et al, 2017; Piers et al, 2011). Documentation of information gathered during family meetings is a measure of good quality EOLC (Koff et al, 2017).

Educating and training ICU teams in identifying patients no longer responding to curative treatments, the need to change goals of care, communicating this transition and delivering quality end of life care should be one of the basic requirements in critical care medicine and nursing. Both Lamba 2012 and Wessman 2017 found positive results in their end of life care pre/post education training programs (Lamba et al, 2012; Wessman et al, 2017). Although Lamba's 2012 sample size was very small, the outcome measures showed a trend towards improved nurse and family quality of death perceptions post intervention period. The results found 1) increased discussions around goals of care in the critically ill liver transplant patients; 2) earlier institution of DNR; 3) increase in time from DNR to death, giving time for relatives to say their goodbyes; 4) decreased length of stay in the SICU; and 5) increase in W/D in the imminently dying patients (Lamba et al, 2012). Wessman 2017 surveyed ICU multi-disciplinary providers pre and post educational intervention with a post intervention response rate 36%. Their findings showed improvements in the domains of work stress, end of life information and space allotment. This study did not evaluate sustainability of this intervention or did they directly survey patients or family members to determine patient centred impact (Wessman et al, 2017).

Summary

Transition of goals of care from curative to end of life care is the terminology used in this literature review. Transition of goals of care is an important component of EOLC to study because there is no standard approach to limiting life-sustaining therapies at the end of life, nor are there any guidelines on how to limit certain therapies in an individualized approach that may involve a stepped trajectory. Educational training focused on specific elements in the transition/end-of-life process found to be beneficial. Better documentation and development of validated tools to measure the quality end of life care transition on the ICU are needed.

There is currently limited guidance on how to manage transitioning from cure to EOL discussions amongst teams. Until such approaches are developed and adopted, intra and interdisciplinary tensions arising from diverse professional motivations for cure within end of life care decision-making will remain (Pattison, 2006).

Table 1: Studies included in review

Authors and Publication	Design	Participants	Method /Aim	Related Theme in Narrative Review	Interpretation of key findings related to transition from cure to care
Adams et al. Intensive Crit Care Nurs. 2013; 29:329-36	Prospective case study	4 family members 1 nurse 2 physicians in ICU	Describe the behaviour of Health Care Professionals and families members through the lens of Adaptive Leadership in a prospective case study of a patient transitioning from curative to palliative care.	Communication Goals of care Family	Behaviors of nurses and physicians facilitated family's ability to adapt to impending death of a loved one. Examples include defining the adaptive challenges for families and foreshadowing a poor prognosis. Decision support realistic hope describe behavior of ICU team and responses of family
Badger. Am J Crit Care. 2005;14:513-21	Qualitative study with interviews	19 female and 5 male ICU nurses	Explore ICU nurses' experiences of moving from cure- to comfort-oriented care and to describe such transitions	Family Goals of care	Nurses felt transition point between cure and comfort-oriented care was unclear. Misunderstanding illness by family, family discord, and shifting medical care decisions made transitions difficult. developing a consensus among patients, patients' families, and staff direction of medical therapy; exhausting treatment options; and patients' lack of response to aggressive medical interventions helped nurses move toward comfort care.
Barwise et al. Mayo Clin Proc. 2018	Retrospective medical files	27,523 patients admitted to the ICU, 779 (2.8%) had limited English proficiency	Determine whether code status, advance directives, and decisions to limit life support different for patients with limited English proficiency (ICU) as compared with patients whose	Communication	Transition process was prolonged with limited English. Patients less likely advance directive, more likely to receive mechanical ventilation, and more likely to have restraints. The Hospital length of stay was 2.7 days longer for patients with Limited English

			primary language was English		
Biskup et al. Swiss Med Wkly. 2017;14;147	Review	Oncology patients in ICU No number specified	provide suggestions for further studies and discusses the need for specific oncological ICU admission and treatment guidelines.	Goals of care- Communication	Oncologists optimistic and intensivists too pessimistic considering cancer patients for an ICU trial unlimited care Need scoring systems and predictive factors Severity of acute illness should be pivotal factor in the decision to provide ICU therapy
Brooks et al. Aust Crit Care. 2016; 30:161-6	Qualitative study with focus groups	11 physicians and 17 nurses	Exploration of perspectives and experiences of physicians and nurses providing EOL care in the ICU. In particular, perceived barriers, enablers and challenges to providing EOL care were examined	Communication Family Education and training	Positive communication, collaboration and culture are vital for high quality care at EOL. Barriers conflict between ICU physicians and external medical teams Availability of education and training Environmental limitations. Enablers collaboration and leadership during transitions of care. Challenges include communication and decision-making, and expectations of the family.
Brooks et al. Am J Crit Care. 2017; 26:336-41	Qualitative study with focus groups	17 nurses and 11 physicians	Exploration of experiences and perspectives of nurses and physicians when initiating end-of-life care in the intensive care unit.	Communication	Timing of End of life difficult conversations. Multidisciplinary acceptance of End of life collaborative decisions Clear organizational processes supporting introduction of nurse and physician end-of-life care leaders essential optimize outcomes for patients, family members, and clinicians.
Chavez et al. PLOS One. 2018;13: e0190569	Retrospective cohort study	10,157 patients received Life sustaining treatments.	Determining risk factors associated with reversals in Life Sustaining Treatments -LST to improve patient and provider epidemiology of critical care inform decision making	Goals of care Family Ambiguous Balance harms and burdens	Advancing age and female gender are associated with decisions to limit LST, even after adjusting for other factors 10,157 patients received Life sustaining treatments- (8.0%) transitioned to comfort care

Coombs J Palliat Nurse. 2010; 16:580-4	Review synthesis of theory and practice	No number specified	Description of the concept of anticipatory grief as opposed to post-death bereavement theories may be important in understanding their needs at critical crisis	Communication Comfort	Synthesis of theory and practice presented here offers an opportunity for fresh insights into clinical and academic practice in bereavement work in ICU. Doctors and nurses need to consider how emotional and social processing in anticipatory grief can be enabled for families in End of life care situations in the ICU
Coombs et al. Int J Nurs Stud. 2012;49:519-27	Qualitative study with interviews	13 medical staff and 13 nurses associated with 17 patients underwent treatment withdrawal	identify the challenges for health care professionals when moving from a recovery trajectory to an end of life trajectory in intensive care.	Ambiguous Goals of care Communication Family	There is currently limited guidance on how to manage transitioning from cure to end of life. Until such approaches are developed, intra and interdisciplinary tensions arising from diverse professional motivations for cure within end of life care decision making will remain
Curtis et al. Am J Respir Crit Care Med. 2016; 19:154-62	RCT	168 patients randomized. 352 family members, 268 participated (76%).	To determine if an intensive care unit (ICU) communication facilitator reduces family distress and intensity of End-of-life care.	Communication Family	Among participants, the intervention reduced ICU and hospital length of stay, decreased family depressive symptoms at 6 months, but they found no significant difference at 3 months or in anxiety or PTSD
Daly et al. J Intensive Care Med. 2018; 33:557-66	Quantitative- survey	264 ICU doctors and family:	Application principles of complexity science in examining extent transitions to end-of- life care can predicted by physician, family, or patient characteristics; outcome expectations; and the evaluation of treatment effectiveness	Family Communication Quality of life	Findings demonstrate the persistent power of a culture that prioritizes length of life over quality of life. Physician expectations for survival and future cognitive status were the only variables consistently and significantly related to the focus of care

Graftieaux et al. Ann Fr Anesth Reanim. 2014; 33:128-34.	Case study	1 Hypothetical patient	Exploration of how best to transition from discussing treatment-withdrawal decisions to discussing possible organ retrieval for donation should the patient die rapidly after treatment withdrawal	Goals of care Quality of life Family	French laws permit Treatment withdrawal with the intention allowing death to occur, that is, to avoid prolongation of the dying process by interventions that are useless, costly, and possibly degrading.
Harvey et al. Br J Anaesth. 2018; 120:138-45	Consensus statement	No number specified	consensus statement is intended to apply where the primary pathology is devastating Brain Injury	Communication Balance harms and burdens Goals of care Family	Incorporating palliative care as part of the end-of-life care in ICU is increasingly accepted as a means of improving the quality of care End-of-life care. Planning should begin at admission to the Emergency department or ICU rather than at the time of making a decision
Kavic et al. Conn Med. 2003; 67:531-4	Retrospective cohort study	61 patients	To define the extent and nature of the End-of-Life decision-making process in critically ill patients.	Consensus Family	In a substantial number of instances transitioned to comfort care at End of life, the family initiated the code-status change. Interestingly, in several cases the family initially withheld advance directives
Knies e al. Semin Neurol. 2016;36:631-41	Review	Neurocritical care no number specified	Review what model of palliative care delivery is optimal	Goals of care Communication	Communication skills that enable clinicians facilitate shared decision making with patients' surrogates are of particular relevance. High-quality decision aids to assist critical care teams and surrogate decision makers during common goals-of-care discussions may have the potential for further promotion of best palliative care practices
Koff et al. Crit Care Med. 2017;45: e379-e38	Retrospective review of patient records	403 deaths or transfer to hospice	To explore differences in the utilization of life support and end-of-life care between patients dying in the medical ICU with cancer	Documentation Quality of life Communication Goals of care	Diagnosis cancer influences intensity of life support utilization and quality of end-of-life care. Patients cancer use less life support and receive better EOLC than patients without cancer. differences are likely due to biases or misunderstandings about trajectory

			compared with those without cancer		of advanced nonmalignant disease among patients, families, and perhaps providers.
Lamba et al. J Pain Symptom Manage. 2012; 44:508-19	Prospective observational pre/post study	79 liver transplant patients = 21 deaths	Hypothesized early communication with physicians/families would improve end-of-life care practice in the LT service patients.	Communication Goals of care Education and training Family	Structured palliative care program was integrated into standard ICU care. Trend toward improvements in “time with family” “breathing comfort” “spiritual services” “presence at time of death” “overall physician care”
Leung et al. Am J Hosp Palliat Care. 2017; 34:729-36	Review	5 papers – 83 patients	Identify the social structures that contribute to decisions for transition from acute care to EOLC for patients with CCI and their families	Communication Goals of care Ambiguity Quality of life Family	Patients and families need help in negotiating meanings of end of life situation and using mechanisms allowing reappraisal and permit understanding as a phase liminal to dying. These mechanisms may paradoxically reduce ambiguity of patients’ future, allowing them to live more fully in the present.
Levin et al. Gen Hosp Psychiatry. 2010;32(4):433-42	Qualitative, critical review	No number of studies specified	Summarize current research and recommendations for ICU EOL communication	Communication Balance harms and burdens	ICU physicians should be trained with EOL communication skills Communication algorithm offered better EOL communication may impact on patient outcomes such as quality of death, bereavement, length of ICU admissions and cost of EOL care
Miller et al. Ann Intensive Care. 2015; 5:59	Retrospective review of patient records	85 medical patients transition to EOLC for medical patients with cancer who died or transitioned to end-of-life on the ICU	Exploration of quality of transition to End of life care using documentary evidence	Goals of care Communication	1. Achieving a consensus to initiate EOL transitions 2. Concomitant prognostication and managing uncertainty 3. Parent medical and critical care team decision-making 4. Integrative palliative care 5. Family-centered versus patient-centered care

Morgan et al. Crit Care Med. 2014; 42:35-61	Retrospective review of patient records	310 ICU patients 95 (30%) had a no escalation of care designation before death.	Determine the prevalence of no escalation of care designation for ICU decedents and identify which interventions are involved	Goals of care Ambiguity Family	No escalation of care designation occurs in a significant proportion of ICU decedents shortly before death. Some interventions are more likely to be limited than others using a no escalation of care approach No standard approach to limiting LST at EOL,
Oud. J Clin Med Res. 2017; 9:23-9	Retrospective cohort study	889,008 elderly hospitalizations with a diagnosis of dementia (6.3%) involved prior admission to ICU	Examination of factors associated with transition to end-of-life care of older adults with dementia and the extent of preceding escalation of care to an ICU setting	Communication Goals of care	Palliative and hospice care communication took place after ICU admission. Communication about alternative care goals was uniformly absent
Pattison. Nurs Crit Care. 2006; 11:198-208	Discourse analysis	Four key UK critical care documents published since 1996	To explore written guidelines and documents for critical care as evidence for the provision of end-of-life	Balance harms and burdens Ambiguity Goals of care	The key documents give little clear guidance about how to provide EOL care in critical care. Discourses include the power dynamic in critical care between professions, families and patients, how impacts on provision of EOL care. Difficulties encountered include dilemmas at discharge and paternalism in decision-making.
Piers et al. Acta Clin Belg. 2011; 66:116-22	Pre-post educational interventional study	115 patients before intervention 113 patients after intervention	Compare the quality of EOL policy between wards and to determine whether a hospital-wide intervention could change the quality of EOL policy.	Documentation Educating Communication Goals of care	Used quality indicators to define quality EOL care pro-active behavior in doctors and nurses achieves quality EOL care Very few had access to high quality end-of-life palliative care.
Robichaux et al. Am J Crit Care. 2006;15:480-9	Qualitative study	21 critical care nurses from 7 facilities	To explore the practice of expert critical care nurses in end-of-life conflicts and to	Ambiguity Goals of care Family	The nurses demonstrated ability and willingness to protect and advocate for vulnerable patients even in situations in which the nurses' actions did not influence

			describe actions taken when the nurses thought continued aggressive medical interventions were not warranted.		the outcomes. The transition from curative to end-of-life care in ICU is often fraught with ambiguity and anguish.
Wessman et al. J Intensive Care Med. 2017; 32:68-76	Pre-post education intervention study	122 doctors and nurses	We hypothesized that multidisciplinary ICU team intervention regarding Goals of care EOL communication will enhance the clinical abilities of providers when discussing EOL issues with patients and families, increase staff comfort level and improve transitions to comfort care approach.	Goals of Care Quality of life-comfort Documentation Communication Education Family	Specific tool for smooth transition improved education, improved family communication and support, improved order sets and improved ICU resources to support EOL care.
White et al. N Engl J Med. 2018; 378:2365-75	Stepped-wedge, cluster-RCT	1420 patients 809 family members completed the entire trial	The study intervention reduces surrogates' long-term burden of psychological symptoms, improve the quality of decision making and clinician-family communication, and shorten the duration of intensive treatment among patients who ultimately do not survive.	Communication, Family	A family-support intervention delivered by the interprofessional ICU team did not significantly affect the surrogates' burden of psychological symptoms, but the surrogates' ratings of the quality of communication and the patient-and family-centeredness of care were better and the length of stay in the ICU was shorter

1.5 Overview of relevant national and International recommendations

1.5.1 Introduction

In the pursuit of investigating all avenues of evidence, a review of existing relevant current national/international guidelines regarding transitions of goals of care from curative interventions to end of life care in the critical care setting was undertaken. Guidelines are developed in an effort to help ensure consistent, evidence-based care of patients using the most up-to-date and relevant knowledge available. After reviewing the guidelines, a comparison of differences and similarities is provided.

1.5.2 Method

A literature search was conducted using the keywords: Recommendations/guidelines ICU end of life care. PubMed, Google, Google Scholar, CINAHL, Cochrane review, and Critical Care web sites were used (<https://www.sccm.org/Research/Guidelines>; <https://www.anzics.com.au/publications/>, <https://www.esicm.org/resources/guidelines-consensus-statements/>).

1.5.3 Findings

Using PubMed, 132 papers were identified whilst the high sensitivity/low specificity of Google Scholar resulted in 114,000 results. Only current (from 2011- 2019) guidelines were used for comparison. Older guidelines were found for example *A consensus statement by the American College of Critical Care Medicine and Statement of the 5th International Consensus Conference in Critical Care* (Truog et al, 2008) but these have largely been superseded by more recent publications so are excluded. Also excluded were National Laws, for example the Law of Dying Patient Israel (Steinberg et al, 2006) Belgium and Dutch law for end of life published (Deliens et al, 2003). Publications included in this table are international recommendations: Consensus document of the Austrian Intensive Care Medicine Societies Recommendations on therapy limit and withholding therapy on intensive care units 2004, II Forum of the "End of Life Study Group of the Southern Cone of America": end of life in intensive care in South American countries 2011.

Primary themes for each document are presented at Table 2

Source	Primary Themes
<i>Statement on Care and Decision-Making at the End of Life for the Critically Ill</i> Australian and New Zealand Intensive Care Society (ANZICS). (2014)	Good medical practice The ethics of end-of-life care The legal framework for end-of-life care Decision-making in intensive care Consensus building, communication and documentation Care of the dying patient, their family and the medical team
<i>Withholding and Withdrawing of Life-Sustaining Treatment: The Canadian Critical Care Society Position Paper</i> Bandrauk, et al (2017)	Guide tool for (ICU) multidisciplinary teams, (EOL) decision-making. Request of a Competent Patient Substituted Decision Making Respectful and Dignified Death Multi-Cultural Considerations
<i>An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units.</i> Bosslet, et al (2015) American Thoracic Society; American Association of Critical Care Nurses; American College of Chest Physicians; European Society Intensive Care Medicine; Society of Critical Care Medicine	Strategies to prevent treatment conflict Proactive communication, for example “potentially inappropriate” should be used, rather than “futile”. Medical profession should lead public engagement efforts and advocate for policies and legislation
<i>Liverpool Care Pathway</i> Ellershaw & Murphy (2011) Governing Body: Marie Curie Cancer Care, UK	Last hours and days of life ensure a death is as dignified and as peaceful, patient as comfortable as possible, address spiritual or religious needs No legal requirement needed to ask patient or relative
<i>Recommendations of the Working Groups from the Spanish Society of Intensive and Critical Care Medicine and Coronary Units (SEMICYUC) for the management of adult critically ill patients</i> Hernandez-Tejedor et al (2017)	Avoid therapeutic futility Consensus Inform patient and family Shared decision making Establish palliative care plan
<i>Shared Decision Making in Intensive Care Units: An American College of Critical Care Medicine and American Thoracic Society Policy Statement</i> Kon, et al (2016)	Definition for Shared Decision Making (SDM), Recommend when SDM should be used, Identify the range of ethically acceptable decision-making models, Present important communication skills: information exchange, deliberation, and making a treatment decision. Define overall goals of care
<i>Guidelines for end-of-life and palliative care in Indian ICU</i> Mani, et al (2012) Governing Body: Indian ICU Society	Physician has a moral and legal obligation to disclose to the capable patient/family and explicitly communicate the standard modalities of limiting life-prolonging interventions Physician must respect choices of the patient/ family Consensus decisions WD or WH decision should be implemented and documented

<p><i>End-of-life care in the intensive care unit.</i> Report from the Task Force of World Federation of Societies of Intensive and Critical Care Medicine (WFSICCM) Myburgh, et al (2016)</p>	<p><u>Provide clarity and direction about global principles of end-of-life care in the ICU</u> Define quality of survival that is acceptable. When decision has been made that LST are to be ceased, use palliative care plan No ethical or legal obligation to provide treatments considered to burden the patient Patient is entitled to refuse shared decision about treatment options documented</p>
<p><i>End of Life care for Adults (QS13)National Institute for Health Excellence - NICE UK (2011)</i></p>	<p>Markers of high-quality care for: adults aged 18 years and older with advanced, progressive, incurable conditions, adults who may die within 12 months, and those with life threatening acute conditions. Support for the families and carers of people in these groups. Making decisions assessing benefit of treatment advanced care planning. Nutrition and hydration CPR versus DNR Holistic measures-psychological, social spiritual and emotional</p>

1.5.4 Discussion

International and cross-society recommendations such as combined American and European Critical Care Societies, World Federation of Critical Care Medicine, Australian and national recommendations from the United Kingdom, Spain, India, principally concentrate on legal issues and common themes include consensus in decision-making and communication. The American College of Critical Care Medicine, The National Institute for Health Care Excellence (NICE), Liverpool Care Pathway and the Canadian position paper refer to all above issues and add symptom control, multi-cultural sensitivity, and dignified death.

In USA, Australia and Western Europe withdrawing life sustaining therapies is more acceptable compared to other countries. The Indian critical care guidelines (Mani et al 2012) are primarily physician directed. Shared decision-making and family/patient consensus, withholding and withdrawing are components of this guideline however, symptom control and nurse involvement are not included. World Federation of critical care produced a position paper endorsing basic ethical principles in end-of-life care delivery (WFSICCM 2012).

Global variations and differences exist reflecting the diversity of human cultures and societies. No singular statement can therefore be regarded as a criterion standard

applicable to all countries and societies. The 2017 Spanish guidelines incorporate communication components in addition provide specific practice for hypothermia after witnessed CPR, as well as specific organ failure treatments, neurological, multi-organ failure, advanced monitoring and documentation. Australian and new Zealand (2014), the Canadian Critical Care Society (Bandrauk, et al 2017) and a collaboration of American and European critical care societies (Bosslet, et al 2015) have produced Policy Statements based on evidenced based published research however they are position statements and suggestions to be used as a guide and an educational tool.

In the UK, the NICE quality standard for end of life care in adults (2011) provide health and social care workers, managers, service users and commissioners with a description of what high quality end of life care looks like, not specific to intensive care. This quality standard contains 16 statements identifying and defining the dying patient, communication, care planning, holistic support, family care, palliative care and after death care. In addition, workforce training and planning guidelines are provided. The quality measures aim to improve the structure, process and outcomes of healthcare. They are not a new set of targets or mandatory indicators for performance management.

Liverpool Care pathway (LCP)

The LCP was developed in the 1990s, using tried and tested integrated care pathway methodology. The 'goals' of care on the LCP were based on the best evidence of optimum care in the dying phase from both the literature and current hospice practice (Ellershaw et al, 2011). The LCP was phased out in 2014 as a result of misunderstanding and uncertainty over decisions to implement LCP as a treatment decision.

In 2013, the LCP attracted significant criticism in the media after concerns were expressed that the use of the LCP hastened people's deaths. It was claimed that over-prescription of painkillers and/or the withdrawal of hydration or nutrition were causing deaths. There were also claims that people were placed on LCP without their consent or their family's knowledge. As a result, the government commissioned an independent review of the LCP. The review looked at evidence, including written

submissions and oral accounts from members of the public regarding their experiences of the LCP (Neuberger et al 2013). The review panel found that, when used properly, the LCP helped patients to have a comfortable, dignified and pain-free death. However, the panel also heard of failings in its use. Whilst research showed that communication between care professionals and families was generally good, there were some instances where it was reported as being very poor. The review panel acknowledged the difficulty of diagnosing when someone is going to die and recognized that, in some instances, placing patients on the LCP caused distress to relatives and carers when the patient then recovered. It also concluded that using the term 'pathway' in relation to people who were dying was inappropriate, and recommended the term be dropped. The review recommended that the use of the LCP should be phased out and replaced with personalized end-of-life care plans for individuals (Neuberger et al, 2013). In June 2014, in response to this review, the Leadership Alliance for the Care of Dying People wrote the report *One Chance to Get it Right* (<https://www.england.nhs.uk/2014/06/approach-to-care/> https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf accessed 23/07/2019) which sets out the approach to caring for dying people that health and care organizations and staff caring for dying people in England should adopt. It identified five priorities for care necessary to achieve good quality care in the last days and hours of life. This approach does not set out a protocol or process that has directly replaced the LCP, but instead details the ways in which care for people who are dying should be responsive to the overall needs and wishes of individuals and their families.

In summary, although ideally based on evidence, recommendations are not mandated and can be time and context sensitive. As we progress in exploring transitions in goals of care we continue to fine-tune and improve end of life care delivery. Patients as well as clinicians differ and variations in illness trajectory exist- every situation and individual are unique. We can choose which recommendations and guidelines are appropriate for our clinical setting, population of patients/families and team cohesiveness.

1.6 Theoretical Framework

The findings of the narrative review and the review of end of life guidelines highlighted the depth and breadth of involvement and investment in transition of curative interventions to end of life care in ICU.

Many countries provide guidance for practice as well as evaluating the quality of care provided and satisfaction with the process (Latour et al, 2009; Yaguchi et al, 2005, Sprung et al, 2003). Understanding when the critically ill patient is no longer responding to life saving curative interventions, moving the focus of care through a transition from maximal efforts to restore full recovery towards the goal of comfort and end of life treatments is a complex issue containing many care processes, physical, emotional and spiritual. The narrative review sheds some light on the framework needed to unravel the complexities into a sensible structure.

The transition period is a process; the narrative review analysis revealed a time period originating from the identification of a turning point in goals of care, evolving into family guidance, communication and instruction regarding this goal transition then moving towards symptom control, family and staff satisfaction with the dying process and finally summation in follow up care. As the process progresses, key points in patients' journey were identified when different practices should be implemented and measured.

Patients start their intensive care journey at a point where their health deteriorates to such a point that drastic measures are needed. At this starting point, this thesis examines the life and death crisis at the patients' cellular level; shock, organ breakdown and the potentially deadly situation, parallel to examining nursing interventions at this stage. The work will be an expression of nursing practices at the cellular level targeting calming and organizing nutrition, fluid balance, organ metabolism as well as emotional stress.

Patients and families are at life threatening crossroads, which present multitudes of moral and ethical quandaries to them as well as with the ICU team. The ethical challenges and dilemmas in this care environment will be demonstrated and discussed. We continue our journey into the examination of ethical, religious, and spiritual challenges and efforts in promoting stability, dealing with conflicts and delivering care during life-threatening and end-of-life situations. When faced with the complexities of some situations ICU nurses report prevalence of moral distress (Ganz et al 2013). Moral distress refers to the painful feelings and psychological disequilibrium experienced when a person knows the appropriate or right thing to do in each situation but cannot carry out that action because of various obstacles or constraints (Ganz et al, 2013). The thesis provides evidenced-based findings regarding the relationship between moral distress and structural empowerment among a national sample of ICU nurses.

Unfortunately, not all ICU admitted patients survive. Overall, mortality rates in adult patients average 10% to 29%, depending on age and severity of illness. Our journey deals with describing nurses' management of transition from curative interventions to end of life care. We will review this transition period, looking at nurses' navigation, leadership roles, and management.

Decision making during the transition period often results in the orchestration of a patients' dying process; to reduce the anxiety and stress during this crisis, nurses' need to work in steering towards a good death experience. This thesis reveals findings on nurses' perspectives on defining a good death. This episode can be directed by nursing composure, calming techniques and patient symptom control, which are significant factors at this stage. A case example will demonstrate nursing skills, practices, and performance resulting in a spiritual, meaningful closure for patient, family, physicians and nurses. We continue our journey into the depths of cultural aspects. Our patients and families as well as multi-cultural staff can sometimes challenge our abilities to control and prevent crisis situations. Often chaos occurs when ICU staff is unfamiliar with ethnicities. Cultural competence is key to calming a cultural diversity as well as

religious and spiritual variables. This thesis will demonstrate nursing tools for promoting multi-faceted competencies.

Our journey delves into communication. One of the central factors in making sense and control many situations, is effective communication. Communication within the ICU team is important for continuity of care. Adequate and efficient nurse handover between shifts is paramount. Non-verbal communication techniques used by nurses are examined in the thesis. Patient and relatives' wishes, culturally important traditions, family structure, their strengths and weaknesses and goals of care are just a few of the significant dynamics, which should be included in the nurse handover.

The journey continues to examine nursing involvement in composing and containing relatives of the ICU patient in life-threatening situations. This body of work includes findings from a nursing intervention that emphasizes family-centred-care, targeted at fulfilling their needs during crisis.

Our journey concludes with recommendations for an evidenced-based care bundle for nurses to use as a toolkit during the transition process. This transition process needs clarification and a structured procedure, which the ICU team can follow in calming this stormy journey. This work will show the common thread of intensive care nursing crisis management, nursing conflict mitigation and calm promoting interventions. The transition of goals from curative interventions to end of life care in the ICU is based on care practices during specific time periods throughout the patients' illness trajectory (Figure 2).

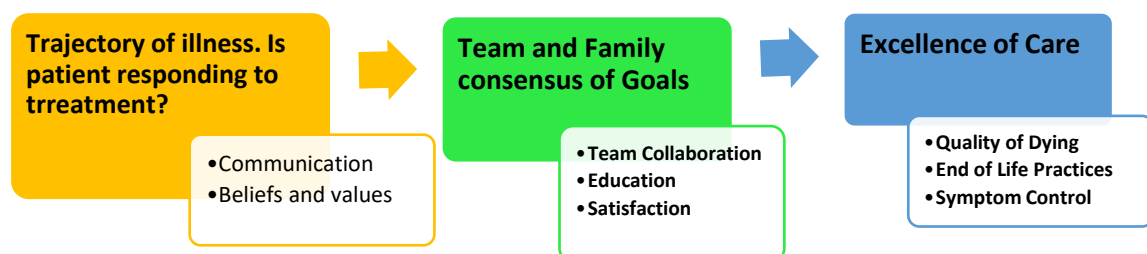


Figure 2. Process of transition from curative to end of life care in the ICU.

1.7 Contribution of the body of work: an end of life care bundle

Defining quality end of life care is culturally, morally, legally and ethically based and can be specific to the ICU environment as well as to the city, country and family/patient. However, some basic concepts have been agreed through international consensus. The term 'orchestrating care at end of life' has evolved from the concepts of withholding and withdrawing active treatment (Sprung et al, 2014). Few tools have been developed to measure how we deliver care at end of life (Mularski et al, 2005). Therefore, based on the narrative review and published studies presented in the previous chapters of this thesis, an ICU end of life care bundle is proposed.

A care bundle identifies a set of key interventions often derived from evidence-based guidelines that, when implemented, are expected to improve patients' health outcomes. The aim of care bundles is to improve health outcomes by facilitating and promoting changes in patient care and to encourage guideline compliance when appropriate (Crunden et al, 2005). The scientific evidence used during the development of this care bundle was derived from relevant world-wide guidelines, scientific evidence findings in narrative review and studies undertaken as part of the doctoral body of work. This thesis proposes the usefulness of end of life care bundle in order to improve patient health outcomes. The implementation of care bundles has been controversial. Robbs' (2010) multi center observational study explored mortality rates in an acute hospital trust in north west London. Eight care bundles of treatments known to be effective in reducing in-hospital mortality were used in the intervention year; adjusted mortality (from hospital episode statistics) was compared to the preceding year. The investigators found that from 2006-7 to 2007-8 there was a 5.7% increase in admissions, 7.9% increase in expected deaths, and 14.5% decrease in actual deaths. Lessons learnt were implementing care bundles can lead to reductions in death rates in the clinical diagnostic areas targeted and in the overall hospital mortality rate (Robb et al, 2010). However, a stepped-wedge cluster-randomized trial of adult patients undergoing emergency open major abdominal surgery was studied to measure the effectiveness of a national quality improvement (QI) program to implement a care pathway (bundle) to improve survival for these patients. The

primary outcome of 90-day mortality occurred in 1210 (16%) patients in the QI group compared with 1393 (16%) patients in the usual care group (HR 1.11, 0.96–1.28). This quality improvement care program aimed at reducing mortality after emergency abdominal surgery had no effect. Just as many patients died in the hospitals implementing the quality improvements as in those providing usual care.

These results cast doubt over the effectiveness of abdominal surgery care bundles on patient outcomes (Peden et al, 2019). It is acknowledged that many bundles lack strong evidence for the efficacy of one or more of their individual components (Aboela et al, 2007). The introduction of care bundles may mandate changes in standard care without the ability to fully monitor the impact of component parts. In 2013 Rello et al performed a multi-center cohort study in five Spanish adult ICUs looking to determine the impact of implementing a care bundle package for VAP prevention on pneumonia rates and duration of mechanical ventilation. They found that some variables might have more impact on improving outcomes than others (Rello et al, 2013). Despite these limitations, care bundles continue to be used to implement behavior change in ICU and can lead to reductions in death rates (Sosnowski et al 2018; Robb et al 2010)

The aim of this thesis is to synthesize findings from the narrative review together with results from my publications to create a practical evidenced based end of life care bundle. The narrative review showed that communication, decision-making and consensus are the primary variables found in the majority of the papers, these factors may be the variables that have the most impact in the end of life care bundle proposed in this thesis.

This body of work represents an international collaborative journey investigating nurses, patients, relationships, practices and theories related to end of life care in the ICU. Together we researched spiritual, emotional, practical and bedside aspects of life and death critical situations and transitions to end of life care. Papers 4-8 depict a transition from curative targeted interventions through culture, religion, ethics, perspectives evolving into collaborative decision-making, end of life care delivery, symptom management and after death care. The narrative review sets the work in the context of other studies in this field conducted in many countries, in order to understand where our future research should take us. Looking at my published works

together with other established evidence in the field of ICU end of life care we can begin to create the next stages of relevant explorations. Taken together, key points, or critical junctures, demonstrated in Figure 3 are identified and provide the basis for a care bundle.

Critical junctures are defined as “relatively short periods of time during which there is a substantially heightened probability that agents’ choices will affect the outcome of interest” (Capoccia and Kelemen 2007, p348). Capoccia’s study of Critical Junctures identified appropriate communication during critical events. Events such as the first visit of the family to ICU, moving a dying patient to a ward or the first discussion with a consultant which can make or break the family’s willingness to accept that the patient may die. Examples such as ‘doctors will sometimes say “well they may not get better” or “they’re unlikely to improve” when actually the patient is going to die’ (Capoccia & Kelemen 2007).

Incorporating the narrative review science with the published papers in this thesis, an end of life bundle is suggested using critical junctures as cornerstones for the framework. The critical junctures are to be used as a timeline for the clinician to consider what needs to be accomplished or addressed during the transition period. Hence, they are prompts rather than recommendations

Components of the Theoretical Model

Today’s challenge for ICU clinicians is to understand and implement patient/family centered end of life desires. By understanding the scientific based critical junctures together with studies integrated in this thesis into everyday practices, we propose that a systematic approach to transition from curative interventions to end of life measures can be implemented. The aim of this integrated model is synthesizing theories, interventional studies and accepted guidelines into a methodological strategy of end of life care processes- from identification of non-responsive patient and assessing life threatening end of life conditions, throughout collaborative decision making. The next step is to then intervene to stabilize the family/patient crisis through cultural, ethical, spiritual, and therapeutic targeted communication. In this journey we incorporate interventions supporting grief, bereavement and follow up care. The components of the model are presented in the below figure and draw on evidence from the narrative review section 1.4 and published papers (papers 1-15).

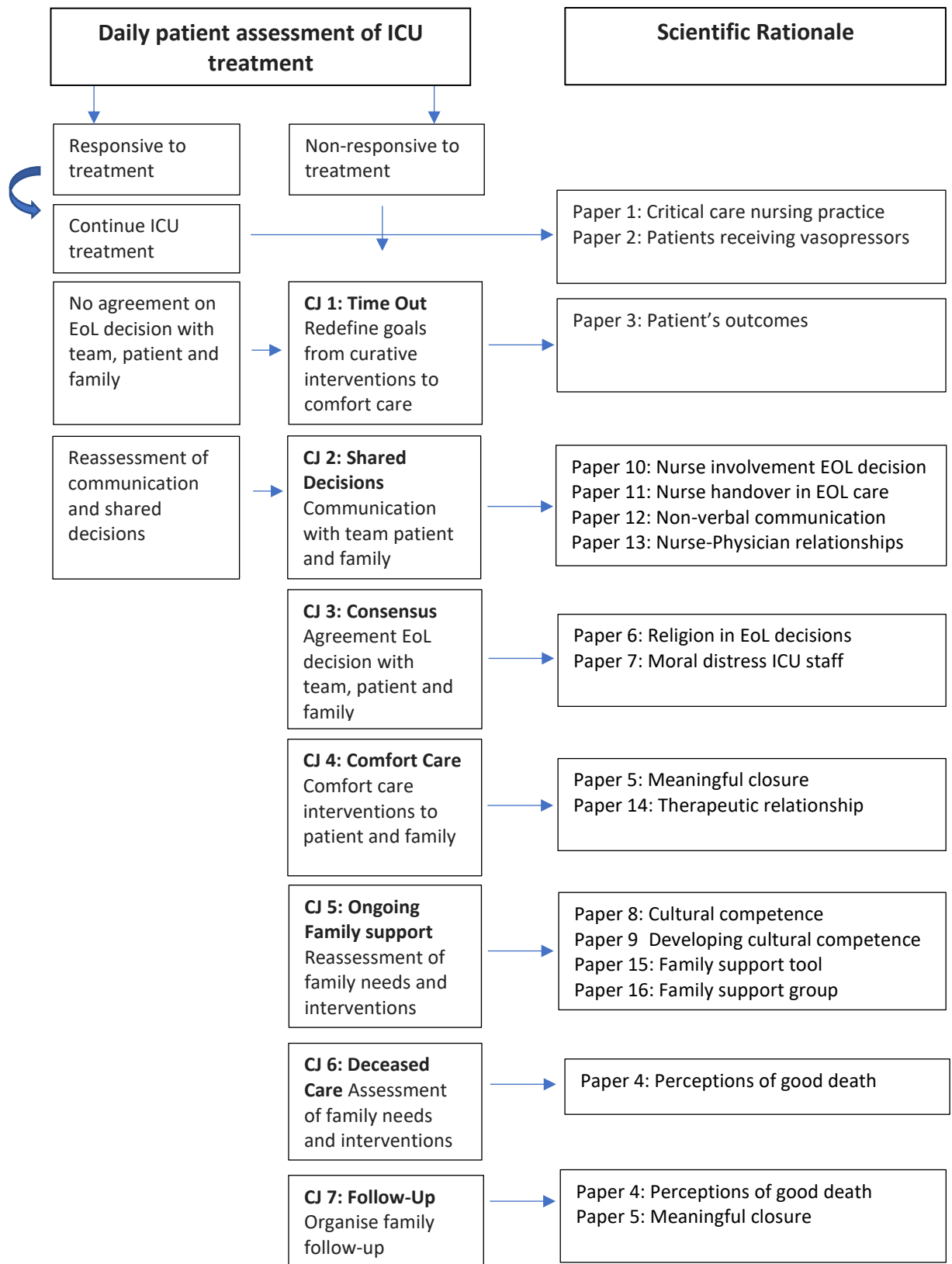


Figure 3. End of life care bundle

CJ=Critical Juncture; ICU=Intensive Care Unit; EoL=End of Life

Critical Juncture 1: Time out (Brooks et al, 2016; Benbenishty et al, 2010; Coombs et al, 2012; Papathanassoglou et al, 2015).

When the health care team identifies that a patient is not responding to treatment; Critical Juncture 1 is then identified. This juncture signifies consideration be given to a change in goals. Regularly each nurses/physician during daily rounds should query every patient – “is this patient responding to curative interventions?” Identification of patients who will not survive is a significant challenge in the intensive care unit (ICU) as the patient’s condition is often complex (Chavez et al, 2018) and death may be an unexpected development during the care trajectory (Harvey et al, 2018). Identification is further compromised by lack of agreement between different disciplines regarding the goals of end of life care. It may be time to redefine target treatment from cure driven interventional measures to care measures directed towards comfort care delivery (Chavez et al, 2018). Backs’ (2014) study of patient and family feedback indicates that patients and families perceive a conversation about goals of care to require disruption of an existing routine, followed by a process of searching and then reconfiguration, rather than a logical decision process. These findings suggest that families and patients prefer proactive suggestions about things “we can do now “and that physicians should suggest goals and plans (Back et al, 2014).

Enabling nurses to identify characteristics of patients not responding to curative interventions and the chances for survival and patient responsiveness is an important step in reassessment of treatment goals and propose a stock take or Time Out. Integrating knowledge of perceptions of what a good death entails, and definitions of quality outcomes are strategies nurses can use as an infrastructure to assist in goal consideration and a call for Time Out.

Critical Juncture 2: Shared decisions (Benbenishty et al, 2006; Azoulay et al, 2009; Ganz et al, 2015; Hartog & Benbenishty 2015).

The aim of practice at this critical juncture is empathetic full team investment in gaining family, team and if possible, patient involvement in decision making on transition of goals of care. Focus on family conferences, must occur early and as often as possible from the same healthcare providers (Curtis et al, 2017).

During this time, the nursing team has opportunities to listen and respond to family, opportunities to acknowledge and address emotions; opportunities to pursue key principles of medical ethics and end of life care, including exploration of patient preferences and to compassionately explain to surrogate decision makers and utilize this time to affirm non-abandonment (Curtis et al, 2005). In order to establish a trustworthy relationship between family and team members, it is essential to assure consistency in communication, we can do that effectively by, define roles of ICU team.

The physician provides daily medical updates to patients' families, offered guidelines for care, and shared medical advice concerning treatment: provide daily goals and options other than curative care (Curtis et al, 2005). Nurses provide daily information to the families offering opportunity to clarify issues; allow time for family to verbalize thoughts, values, interpretation of patient's wishes; is present as a non-coercive, nonjudgmental "sounding board" as families processed their thoughts and feeling; reinforce goals of care (Ahrens et al, 2003) In cases where communication does not result in team/family/patient consensus then the team should reassess the decision-making process to identify improvement mediator issues. In addition, this is a prime opportunity to sit face to face with disagreeing partners to understand their perceptions.

Nurses use a wide range of skills in decision-making and assisting patients/families in their decision-making (Benbenishty & Hannink 2015). Learning culturally specific assessment tools, addressing moral and ethical dilemmas and conflicts within the family and ICU team is crucial in the end of life process (Benbenishty & Biswas 2015). Religion and spirituality are fundamental beliefs which when applied may alleviate distress and emotional suffering (Benbenishty 2014). These beliefs should be openly addressed, and the nursing approach should be subtle and gentle in application. When nurses use their training and knowledge in all these aspects in their approach to caring for patients at end of life, they rely on the above arsenal of tools, for example using nonverbal communication strategies, active listening and cultural and spiritual assessment questionnaires (Benbenishty 2014; Benbenishty & Biswas 2015). These

are just a few of the many multi-variable competencies' nurses need in order to deliver good holistic nursing end-of-life care (Endacott et al, 2016).

Critical Juncture 3: Consensus (Latour et al, 2009; Bülow et al, 2012; Ganz et al, 2013; Lamba et al, 2012).

Several studies found that physicians do not take the time to clearly understand the surrogate decision makers' perception and understanding of the decisions made (Curtis et al, 2005; Azoulay et al, 2009; Ganz et al, 2013). When families meet with ICU physicians, they frequently have insufficient time to share their perspectives on the patient's goals and values or express their own concerns (Badger et al, 2005). ICU physicians may miss opportunities for empathic response to emotions, leaving families too distressed to absorb or integrate information they need for surrogate decision-making (Barwise et al, 2018; Curtis et al, 2005).

In this juncture it is imperative that the ICU nurse uses assessment skills to assure complete comprehension (Benbenishty & Hannink 2017). Conflicts exist over some patients whose families insist on care that ICU team consider inappropriate and hence inadvisable, and over other patients whose families object to care that physicians prefer to provide. When such conflicts occur, mediation between families and health care team is usually successful in resolving it (Adams et al, 2013).

The opportunity to listen carefully to family members' concerns and respond directly to these concerns is an important component of these discussions (Benbenishty & Hannink 2017). The nurse needs to probe the surrogate decision maker ensuring that they realize the scope and implications of the end of life decision. Whether it be only non-escalation of therapy to withdrawal of interventions, the nurse should take the time to fully explain the complete implication of every decision (Benbenishty & Hannink 2017). The nurse should assess family/patient that they understand that all measures have been exhausted and instruction and guidance to family and patient that transition to end of life care does not mean "no care" (Badger et al, 2005).

Asking questions like “tell me what the doctor told you. Describe what you understood what the physician said” have been found to be helpful (Back 2014). Communication is one of the most important competencies needed in end-of-life care (Biskup et al, 2017; Brooks et al, 2016; Coombs et al, 2010). Communication includes many expertise, from active listening, comprehension, nonverbal to expression of empathy and hope when confronted with death (Benbenishty & Hannink 2015). The studies in this section present an overview of the various types of communication and how important they are in end of life care (Ganz et al, 2013; Adams et al, 2013; Daly et al, 2018; Lamba et al, 2012). Proper, quality communication in nurse handover is paramount in the continuum of care (Ganz et al, 2015). Many of the published studies repeatedly show family dissatisfaction with ICU care because of too many different clinicians relating varied messages (Chavez et al, 2018; Koff et al, 2017; Miller et al, 2015). Miscommunication leads to distrust and conflicts (Luce 2010). Once the team misses the opportunity to establish trust and engage the family prospects are gone (Curtis et al, 2005). Conflicts within the nurse-physician team should be resolved before approaching the family (Azoulay et al, 2009; Hartog & Benbenishty 2015). The studies in this section enlighten fundamentals of the therapeutic factors in the patient- nurse relationship (Benbenishty & Hannink 2017), discuss how our non-verbal communication strongly impacts patient trust, (Benbenishty & Hannink 2015) aspects of physician-nurse conflicts and how our communication during handover contributes to end of life care practices (Hartog & Benbenishty 2015).

Critical Juncture 4: Comfort care (Badger et al, 2005; Coombs et al, 2010; Benbenishty 2014; Benbenishty & Hannink 2017).

This juncture focuses on providing symptom management and comfort care including frequent turning, washing, mouth and eye care, massage with perfumed lotion, combing and grooming as well as frequent family visits. If the patient is conscious then emotional and spiritual support is offered (Adams et al, 2013; Benbenishty 2014). A clergyman may be called, patient choice music can be played, and other spiritual customs and rituals can be suggested (Holm et al, 2012).

Nurses have described how they used their senses to read patients' bodily experiences, their needs for extensive and 'trifling' nursing care, and whether their actions had the desired effects (Coombs et al, 2010; Benbenishty & Hannink 2015). It can be maintained that it is not until nurses can master machinery and procedures that they can focus on patients as human beings and their needs, enabling the patients to tolerate the often-afflicting technology on their bodies (Ganz et al, 2013). Furthermore, nurses use their hands to palpate patients' bodies to assess their state. This is called 'diagnostic touch,' and is mainly executed with an intellectual hand, which analyses, dissects, and makes diagnoses and prognoses (Benbenishty & Hannink 2015).

Endacott, 2016 found that most ICU nurses defined "a good death "as being able to delivery pain free care, closure and keeping the patient as clean as possible (Endacott et al, 2016).

Intensive care nurses perceive adequate patients' pain management, agreement between health professionals on decision-making, and facilitating a comfortable environment for patients and families, during the whole end-of-life process as a priority of care delivery at end of life (Endacott et al, 2016). This bundle component is essential throughout the transition process and becomes paramount in nursing care delivery when all curative interventions cease. Good nursing care related to patients' exhaustion in suffering was described as aiming to reduce patients' afflictions and pains and enhancing their comfort (Isaacson et al, 2017). A qualitative study found patients described nursing end of life care and caring throughout the transcripts most often in relation to compassion. The connection between compassion and caring was so strong that many participants did not delineate between the two, often substituting 'compassion' for 'care' and 'caring' throughout the interviews (Bramley & Matiti 2014). Martins & Basto 2011 demonstrated nursing interventions which relieved patient's end of life suffering. These interventions were developed through a process that is interactional, dynamic, integral and systematic. The process included nurses who assisted patients in the last hours of life by providing physical comfort, accepting the reality of their condition, supporting the emotional equilibrium, harmonizing the

environment, and facilitating friends and family presence. Nurses enable final wishes, spiritual and comfort needs (Martins & Basto 2011).

Good nursing care related to patients' loneliness aimed to maintain patients' meaningful relations and feelings of not being abandoned (Benbenishty 2014). This was confirmed by nurses' presence and assurances that they would not leave the patient (Fridh et al, 2009). The nurses thought that a patient's dignity was threatened when he/she was over-treated, for instance when relatives wanted the patient to go on living for their sake, or when physicians decided to continue treatment for dying patients (Fridh et al, 2009). The nurses also highlighted patients' loss of dignity in relation to changes in appearance: Good nursing care related to patients' loss of control and retaining dignity was described as treating every patient respectfully as a conscious, awake and unique person (Endacott et al, 2016). To enhance his personality in the daily care, relatives were encouraged to characterize the patient, to give advice, and bring a picture of the patient to remind him about his previous appearance (Fridh et al, 2009).

End of life factors rated important among patients included having funeral arrangements planned, feeling that one's life was complete, not being a burden to family or society, being able to help others, coming to peace with God, and praying (Benbenishty 2014). Although most ICU patients are not conscious at EOL, these important factors can be implemented by family members with the assistance of the bedside nurse (Benbenishty 2014).

Critical Juncture 5: Ongoing Family Support (Daly et al, 2018; Benbenishty 2015; Kirshbaum-Moriah et al, 2016; Benbenishty 2015). Family care should be provided throughout the entire stream – although we are caring for the patient at this end of life stage- the family needs our support and care in a parallel fashion. This junction CJ 5 was specifically labeled family care in order to insure that families' needs are met during this period.

Directing practice towards the family when their loved one is going through this transition trajectory is imperative for the impending death to be perceived as a quality experience (Coombs et al, 2012). Therefore, the nurse must perform family assessment of cultural, emotional, spiritual, and physical needs (Benbenishty & Biswas 2015). Query what their expectations and hopes might be. Reassure them that the family and patient will not be abandoned the ICU nurse can provide explanation and guidance to the family of what they can do for patient and themselves to assure a meaningful closure (Benbenishty 2014).

Some additional tools have been evaluated to support patients, families, and clinicians (Lamba et al, 2012; Curtis et al, 2012). A multicenter study in Europe evaluated a diary intervention in which healthcare staff and family contributed to a handwritten diary recording events and experiences daily during the patient's ICU stay (Jones et al, 2010). Another tool included the development of standardized order sets to support clinicians, prepare families, and ensure patient comfort during limitation of life support (Wessman et al, 2017). A Dutch study found that families were satisfied with the overall quality of death and dying. They felt supported by the ICU caregivers (Gerritsen et al, 2013). Families of patients dying in Dutch ICUs are satisfied with the quality of end-of-life care as well as the quality of the dying process. The families felt strongly involved in the decision-making process regarding outcome (Gerritsen et al, 2013). In a United States ICU a structured palliative care program to improve the quality of end-of-life care was integrated into standard care. The intervention was designed to apply to all patients and their families regardless of their prognosis. Implementation of the intervention changed the qualitative nature of physician rounds and practice. Palliative care domains introduced during the study period were pain, other symptom management, bereavement/family support, goals-of-care discussions, shared decision making, and conflict resolution. Goals-of-care discussion on physician rounds increased from 2% to 39% of patient-days during the intervention period. Their findings demonstrate that integration of early palliative care alongside an aggressive, disease-focused, curative care can be accomplished in the ICU for patients without change in mortality and has the ability to improve the end-of-life care practice in such patients (Lamba et al, 2012).

During this critical juncture the nursing care provided to family members during this sad and stress filled process is key in family and staff satisfaction and perception of a quality death in the ICU (Endacott et al, 2016).

What new interventions can we create to improve communication, alleviate family anxiety during this devastating life-threatening crisis? We need to incorporate variables, skills and competencies, discussed in previous chapters. What interventions can nurses implement which is cost effective, to support families and promote coping sustainability? By creating a family support group while their loved one is hospitalized in ICU has shown promise in fulfilling family needs while at the same time proving nurses with essential knowledge regarding family capabilities (Benbenishty 2015; Kirshbaum-Moriah et al, 2018). The body of extensive work from qualitative and quantitative nursing family support group interventions shows new possibilities for nurses to implement change in their support of ICU families.

Critical Juncture 6: Deceased Care (Endacott et al, 2016; Lemiale et al, 2010; van der Klink et al, 2010)

This juncture is the time when nurses care for the deceased body. The Efstathiou & Walker 2014 study found that a good death means to promote comfort as a result of therapeutic interventions ensuring the right to physical integrity, preserving the good body image and ensuring dignity (Efstathiou & Walker 2014). Vigilance, non-abandonment, composure-being present and providing a meaningful spiritual closure all encompass after death care (Benbenishty 2014). Ensuring a good death means above all to promote comfort through nurse care practices that reconcile rationality and sensibility ensuring the dignity of the patient and his family (Endacott et al, 2016). Nurses must also identify the importance of considering the place of death [moving to a single room], whether the family can be present and aware of what was going to happen, whether the dying patient was pain free, and calm [no agitation or fitting] (Badger et al, 2005).

Nurses should remove monitoring equipment from the close proximity of the patient and family to 'de-intensify' the environment so that the "patient is given back to the family as they came to us" (Endacott et al, 2016). In this way the nurse could construct the death that best represented what he/she perceived a good death to be both professionally and personally (Badger et al, 2005).

A study of EOL post death nursing practice found that nurses move patients to private rooms for family privacy, to ensure peaceful dignified bedside scene. The nurses focused on enough family time next to the deceased body to accept the new reality (Fridh et al, 2007).

A Norwegian nursing study demonstrates that music might be helpful for nurses during after-death care as well as for the care of the relatives. Including ambient music in an after-death care can help nurses show respect and dignity to the deceased patient (Holm et al, 2012). This juncture includes nurse explanation to family regarding death certificate and hospital procedures.

Critical Juncture 7: Follow-Up (McAdam et al, 2016; van der Klink et al, 2010).

This juncture focuses on determining how relatives of deceased ICU patients had experienced the care given to their loved one and to find out if information and care provided were sufficiently meeting family needs and related to their bereavement process (Jones et al, 2018). A visit to the ICU after critical illness and death can be a way for the family to bring their time in the ICU to a close. After the death of a loved one, bereaved family members may still be faced with questions or issues and may leave the ICU unsatisfied or confused. According to McAdam & Erikson (2016) a bereavement follow-up service could enhance family members' adaptation to life without their loved one and help ameliorate negative physical and emotional reactions to unresolved grief (McAdam & Erikson 2016). In van der Link 2010 study investigating family bereavement 35.3% reported a need for a bereavement follow-up service (van der Klink et al, 2010). The main reason according to respondents was: 'For remaining questions. One respondent added that 'despite the severity of the situation, it is crucial to give the family members clear information, so they will suffer

less problems afterwards (van der Klink et al, 2010). Follow-up services have the capacity to enhance family members' adaptation to life without their loved one and help ameliorate negative physical and emotional reactions to unresolved grief (Fauri et al, 2000). Common features of these programs are an initial phone call, card or letter from a caregiver who knew the patient and the family, a family meeting for remaining questions and if necessary, referral to other agencies (Cuthbertson et al, 2000; van der Klink et al, 2010). Fridh's Swedish study found that many units reported (51%) that they often or almost always offer a follow-up visit, although in most cases the bereaved family had to initiate the follow-up by contacting the ICU (Fridh et al, 2007). According to the respondents, almost half of the families of patients who die in Swedish ICUs are seldom or never offered a follow-up visit/meeting. Some units distribute a leaflet including telephone numbers before the family leaves the unit after the patient's death (Fridh et al, 2007). Another important advantage of such follow-ups is that they may lead to improvement in the care of dying patients and their families. Without gaining knowledge from families' experiences, both good and bad, future EOLC cannot be improved.

In summary, integrating publications included in this thesis into a proposed nursing EOLC bundle can change and influence care of our patients at EOL. Synthesizing the evidence into a sensible, continues bundle of EOLC practices results in a model demonstrating the incorporation of critical junctures in transition from curative interventions to end of life measures. This framework structure combines the complex steps needed for this transition in ICU end of life setting; incorporating the eight evidenced based themes found in scoping the published evidence. A care bundle containing the elements described and tested will be next step in ICU end of life exploration.

1.8 Significance of Work to Clinical Practice

The proposed thesis will be a kaleidoscope perspective of nurses providing care in life threatening and end-of-life situations to patients and families in intensive care. Defining life-threatening and transitions to end-of-life in ICU is a difficult process demanding depth of vision, width of understanding complex physiological and holistic conditions and multi-dimensional resolution of conflicts, ethical challenges, cultural competencies and environmental variances. This work examines the nursing thread of care throughout life-threatening and transitions to end-of-life care and a good death. The thesis incorporates multi-factorial analysis of confounding factors influencing care delivery between curative measures to end of life treatment practices. This thesis provides integrative information regarding chaotic crisis situations in critically ill patients' physical state, cognitive and mental deterioration, and familial and social dysfunction. Along with this, the studies will demonstrate evidenced-based findings, which nurses can use to intervene and manage these circumstances.

1.9 Future Perspectives

The possibilities of future applications of the thesis are varied. The work could be a basic infrastructure foundation for the development of a nursing model for an end-of-life nursing care practice bundle. Using the variables, skills, interventions demonstrated in this body of work can be used to formulate the bundle. The scientific foundation is grounded, competencies are identified, and results are evaluated for such a bundle. The science offered in this work demonstrates broad, extensive, worldwide applicability for nursing practice. This work reveals multi-faceted, international perspectives from the cellular level, family, team and social value of the therapeutic relationship nurses create. Combining the components of the conclusions and results depicted in this work can be used for educational curriculum in teaching an evidenced based, multi-dimensional practical model for good end-of-life care delivery.

Some quality indicators for measuring end of life ICU care have been published. In 2003 a consensus report was published regarding the key end of life domains in the intensive care unit. Quality performance indicators within each domain were established based on review of the literature and an iterative process involving the authors and members of the RWJF Critical Care End-of-Life Peer Workgroup (Clarke et al 2003). Missing domains are spiritual, religious, existential and cultural aspects. These indicators have yet to be systematically validated. In 2006 Nelson published a practical set of measures for routine monitoring, performance feedback, and improvement in the quality of palliative care in the intensive care unit. The new bundle of measures established a prototype for routine measurement of the quality of palliative care in the ICU. These indicators have yet to be validated internationally (Nelson et al, 2006). The recently published Faculty of Intensive Care Medicine 2019 guidelines can also be used as quality indicators

In 2017 Leung et al tested and evaluated the quality of end-of-life care in a Hong Kong ICU. They found Quality indicators consisting of 4 domains and 12 indicators were devised. The four domains were early identification of dying patients; communication and information; end-of-life care to the patient and care

after death. They applied these indicators to assess the EOLC of patients who died in a 20-bed mixed ICU. Areas for improvement included early identification of dying patients; training on assessment of the social, psychological and religious needs of the patient's family; distribution of information leaflets; assessment and management of symptoms; and regular review of the process (Leung, et al 2017).

In my future programme of measuring quality indicators based on the end of life care bundle in this thesis will include different methodologically and scientific approaches compared to previously published measures. I aim to test the bundle as a complex intervention using the MRC framework (Craig 2008). Many of the developmental components of the MRC framework have been developed; the next stage would be to test the bundle in a feasibility study followed by a multicentre, multi-country, stepped wedge clinical trial.

Nursing's foundational principles and guidelines state that, as a profession, nursing has a responsibility to measure, evaluate, and improve the quality of nursing practice. Nursing sensitive quality indicators are an important part of the equation when it comes to establishing evidence-based practice guidelines (Montalvo (2007). However, measuring these indicators is not simply good science – it is an ethical requirement. Therefore, I will test this end of life care bundle using quality indicator tools measuring the quality of death and nursing interventions included in the bundle. My future steps will be in a mixed-method, interventional design using ICU team members as well as family outcome measures. The euroQ2 questionnaire- quality of death and dying validated in families from Denmark and the Netherlands will be used as the quality indicator tool evaluating the end of life care bundle. This tool has been used to evaluate 91 Dutch and 126 Danish families' perspective of quality of end of life care in multiple intensive care units (Gerritsen, et al 2018). The same tool would be used to evaluate the ICU teams (physicians and nurses) perceptions of care before and after implementing the end of life care bundle proposed in this thesis.

We will not use family symptoms of long-term depression, anxiety, or post-traumatic stress as outcome measures, but family perceptions of a good death experience. Compared to the Liverpool care pathway, where there were concerns around treatment decisions being made without relatives being informed, family members not being told that their loved-one was dying and hurried, this bundle is

centered on communication and consensus. This current bundle contains junctures where family involvement and care is essential and paramount, consensus, shared decision- making and cultural sensitivity is a primary competence. My expectation would be a national or international trial using nurses currently working in ICU. The quantitative measure of the End of life care bundle together with in depth focus group qualitative analysis would add richness; incorporate culture, spiritual, educational, religious variables to be a foundation for future research endeavours.

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PART A

IDENTIFICATION OF TRANSITION IN GOALS OF CARE

Paper 1

Differences in European critical care nursing practice: a pilot study

Julie Benbenishty, Freda DeKeyser Ganz, Sheila Adam

Intensive and Critical Care Nursing 2005;21:172-178

DOI:10.1016/j.iccn.2004.08.004

Paper 2

Characteristics of patients receiving vasopressors

Julie Benbenishty, Charles Weissman, Charles L. Sprung, Mali Brodsky-Israeli, Yoram Weiss

Heart & Lung 2011;40 (3):247-252

DOI: 10.1016/j.hrtlng.2010.04.007

Erratum: Figure 3: the y-axis should be labeled: Survival

Table 3 should be labeled: Significant risk factors for mortality

Paper 3

Research advances in critical care: Targeting patients' physiological and psychological outcomes

Elizabeth Papathanassoglou, Ged Williams, Julie Benbenishty.

BioMed Research International 2015 Article ID 283067

DOI: <http://dx.doi.org/10.1155/2015/283067>.

Paper 4

Perceptions of a good death: A qualitative study in intensive care units in England and Israel

Ruth Endacott, Cindy Boyer, Julie Benbenishty, Maureen Ben Nunn, Helen Ryan, Wendy Chamberlain, Carole Boulanger, Freda Dekeyser-Ganz

Intensive and Critical Care Nursing, 2016; 36, 8-16

DOI: <http://dx.doi.org/10.1016/j.iccn.2016.04.004>

PART B

CULTURAL, RELIGIOUS, ETHICAL AND SPIRITUAL COMPETENCIES OF NURSES IN ICU

Paper 5

A meaningful closure

Julie Benbenishty

Intensive Care Medicine, 2014;40(11):1758-1759

DOI 10.1007/s00134-014-3359-8

Paper 6

Are religion and religiosity important to end-of-life decisions and patient autonomy in the ICU? The Ethicatt study

Hans-Henrik Bülow, Charles L. Sprung, Mario Baras, Sara Carmel, Mia Svantesson, Julie Benbenishty, Paulo A. Maia, Albertus Beishuizen, Simon Cohen, and Daniel Nalos

Intensive Care Medicine 2012;38(7):1126-1133

DOI: 10.1007/s00134-012-2554-8

Paper 7

Moral distress and structural empowerment among a national sample of Israeli intensive care nurses

Freda DeKeyser Ganz, Ofra Raanan, Rabia Khalaila, Kochav Bennaroch, Shiri Scherman, Madeleine Bruttin, Ziva Sastiel, Naomi Farkash Fink and Julie Benbenishty

Journal of Advanced Nursing 2013;69(2):415-424

DOI: j.1365-2648.2012.06020.x

Paper 8

Cultural competence in critical care: Case studies in the ICU

Julie Benbenishty, Seema Biswas

Journal of Modern Education Review 2015;5(7):723-728

DOI: 10.15341/jmer (2155-7993)/07.05.2015/011

Paper 9

Developing cultural competence in clinical practice

Julie Benbenishty, Seema Biswas

Journal of Modern Education Review 2015;5(8):805-811

DOI: 10.15341/jmer (2155-7993)/08.05.2015/009

PART C

NURSE COMMUNICATION SKILLS IN CRITICAL SITUATIONS

Paper 10

Nurse involvement in end-of-life decision making: the ETHICUS Study

Julie Benbenishty, Freda DeKeyser Ganz, Anne Lippert, Hans-Henrik Bulow, Elisabeth Wennberg, Beverly Henderson, Mia Svantesson, Mario Baras, Dermot Phelan, Paulo Maia, Charles L. Sprung

Intensive Care Medicine 2006;32:129-132

DOI: 10.1007/s00134-005-2864-1

Paper 11

The quality of intensive care unit nurse handover related to end of life: A descriptive comparative international study

Freda DeKeyser Ganz, Ruth Endacottc, Wendy Chaboyer, Julie Benbenishty, Maureen Ben Nun, Helen Ryan, Amanda Schoter, Carole Boulanger, Wendy Chamberlain, Amy Spooner

International Journal of Nursing Studies 2015;52(1):49-56

DOI: <http://dx.doi.org/10.1016/j.ijnurstu.2014.07.009>

Paper 12

Non-verbal communication to restore patient-provider trust

Julie Benbenishty and Jordan Hannink

Intensive Care Medicine 2015;41(7):1359-1360

DOI 10.1007/s00134-015-3710-8

Paper 13

Understanding nurse-physician conflicts in the ICU

Christiana S Hartog, Julie Benbenishty

Intensive Care Medicine 2015;41(2):331-333

DOI 10.1007/s00134-014-3517-z

Paper 14

Patient perspectives on the influence of practice of nurses forming therapeutic relationships

Julie Benbenishty and Jordan R Hannink

International Journal for Human Caring 2017;21(4):208-213

DOI: <https://doi.org/10.20467/humancaring-d-17-00060>

Part D

Nursing interventions promoting family members' coping

Paper 15

Family support group: a tool for nurses

Julie Benbenishty

Nursing in Critical Care 2015;20(6):282-283

DOI: 10.1111/nicc.12228

Paper 16

Family Members' Experience of Intensive Care Unit Support Group: qualitative analysis of intervention

Dvora Kirshbaum-Moriah, Chaya Harel and Julie Benbenishty

Nursing in Critical Care. 2018;23(5):256-262

DOI: [10.1111/nicc.12272](https://doi.org/10.1111/nicc.12272)

PUBLICATIONS INCLUDED IN THESIS

This thesis contains published work, all of which has been co-authored. The bibliographical details of the work, a description of the work, and an estimated percentage of contribution (%) of each author are listed below. The declarations of the lead authors are listed in Appendix B.

Original research

Benbenishty, J., (70%) DeKeyser, F., (10%) Adam, S. (20%) (2005) Differences in European critical care nursing practice: a pilot study. *Intensive and Critical Care Nursing* 21; 172-178.

Julie Benbenishty wrote the research protocol, transcribed and interpreted the data and drafted the manuscript. All other authors provided guidance for data analysis and critically reviewed the manuscript.

Benbenishty, J., (65%) DeKeyser Ganz, F.,(10%) Lippert, A., (2%)Bulow, HH.,(2%) Wennberg, E,(2%) Henderson, B.,(2%) Svantesson, M.,(1%) Baras, M.,(2%) Phelan, D.,(2%) Maia, P., (2%)Sprung, C.(10%) (2006) Nurse involvement in end-of-life decision making: the ETHICUS Study. *Intensive Care Medicine* 32; 129–132.

Julie Benbenishty was responsible for contributing to protocol development and writing, data collection, ethical approval, and data interpretation as well as primary contribution to manuscript creation. All other authors contributed to data collection in their countries, and critically reviewed the manuscript.

Benbenishty, J., (75%) Weissman, C. (10%), Sprung, C. (5%), Brodsky-Israeli, M. (5%), Weiss Y. (5%) (2011) Characteristics of patients receiving vasopressors. *Heart Lung* 40; 247-52.

Julie Benbenishty conducted the literature review, data extraction, interpreted the data and drafted the manuscript. All other authors contributed to interpretation of the data and critically reviewed the manuscript.

Benbenishty, J., (80%) Hannink, J. (20%). (2017) Patient Perspectives on the Influence of Practice of Nurses Forming Therapeutic Relationships. *International Journal of Human Caring* 21(4), 208-213.

Julie Benbenishty conducted the literature review, wrote the research protocol, interpreted the data and drafted the manuscript. All other authors contributed to interpretation of the data and critically reviewed the manuscript.

Bülow, H., (50%) Sprung, C., (10%) Baras, M., (5%) Carmel, S., (5%) Svantesson, M., (5%) **Benbenishty, J., (15%)** Nalos, D. (10%) (2012). Are religion and religiosity important to end-of-life decisions and patient autonomy in the ICU? The Ethicatt study. *Intensive Care Medicine* 38; 1126-1133.

Julie Benbenishty conducted the literature review, contributed to research protocol development, interpreted the data and drafted the nursing aspects of the manuscript. All other authors contributed to interpretation of the data and critically reviewed the manuscript.

Ganz, F. D., (40%) Endacott, R., (20%) Chaboyer, W., (10%) **Benbenishty, J., (15%)** BenNunn, M., (5%) Ryan, H., (5%) Spooner, A. (5%) (2015). The quality of intensive care unit nurse handover related to end of life: A descriptive comparative international study. *International Journal of Nursing Studies* 52; 49-56.

Julie Benbenishty was responsible for contributing to protocol development and writing, data collection, ethical approval, and data interpretation as well as contribution to manuscript creation. All other authors contributed to interpretation of the data and critically reviewed the manuscript.

Endacott, R., (40%) Boyer, C., (20%) **Benbenishty, J., (20%)** BenNunn, M., (5%) Ryan, H., (5%) Chamberlain, W., (5%) Ganz, F. D. (5%) (2016). Perceptions of a good death: A qualitative study in intensive care units in England and Israel. *Intensive and Critical Care Nursing* 36; 8-16.

Julie Benbenishty assisted in writing the research protocol, responsible for ethical approval, transcribed and interpreted the data and drafted the manuscript. All other authors provided guidance for data analysis and critically reviewed the manuscript.

Ganz, F.D., (25%) Raanan, O., (10%) Khalaila, R., (5%) Bennaroch, K., (5%) Scherman, S., (10%) Bruttin, M., (10%) Sastiel, Z., (10%) Fink, N.F. (10%) **Benbenishty, J., (15%)** (2013) Moral distress and structural empowerment among a national sample of Israeli intensive care nurses. *Journal of Advanced Nursing* 69; 415-424.

Julie Benbenishty was responsible for writing the research protocol, gaining ethical approval, supervising multi-centered trial data collection and interpretation and contributed to the creation and publication of the manuscript. All other authors provided guidance for data analysis and critically reviewed the manuscript

Kirshbaum-Moriah, D., (35%) Harel, C., (20%) **Benbenishty J., (45%)** (2016) Family members' experience of intensive care unit support group: qualitative analysis of intervention. *Nursing in Critical Care* 21; 341-349.

Julie Benbenishty wrote the research protocol, responsible for ethical approval, supervised the data collection and transcription and interpreted the data and drafted the manuscript. All other authors provided guidance for data analysis and critically reviewed the manuscript

Conceptual papers

Benbenishty, J., (80%) Hannink, JR. (20%) (2015) Non-verbal communication to restore patient-provider trust. *Intensive Care Medicine* 41; 1359-60.

Julie Benbenishty wrote the research protocol, responsible for ethical approval, transcribed and interpreted the data and drafted the manuscript. All other authors provided guidance for data analysis and critically reviewed the manuscript

Benbenishty, J., (100%) (2014) A meaningful closure. *Intensive Care Medicine* 40; 1758-1759.

Julie Benbenishty wrote the research protocol, responsible for ethical approval, transcribed and interpreted the data and drafted the manuscript. All other authors provided guidance for data analysis and critically reviewed the manuscript

Benbenishty, J., (75%) Biswas, S. (25%) (2015) Cultural Competence in Critical Care: Case Studies in the ICU. *Journal of Modern Education Review* 5; 723-728.

Julie Benbenishty wrote the research protocol, responsible for ethical approval, transcribed and interpreted the data and drafted the manuscript. All other authors provided guidance for data analysis and critically reviewed the manuscript

Benbenishty, J., (80%) Biswas, S. (20%) (2015) Developing Cultural Competence in Clinical Practice. *Journal of Modern Education Review* 5; 805-811.

Julie Benbenishty wrote the research protocol, responsible for ethical approval, transcribed and interpreted the data and drafted the manuscript. All other authors provided guidance for data analysis and critically reviewed the manuscript.

Hartog, CS., (50%) **Benbenishty, J., (50%) (2015) Understanding nurse-physician conflicts in the ICU. *Intensive Care Medicine* 41; 331-3.**

Julie Benbenishty has contributed and written the nursing aspects of this paper. All other authors provided guidance for data analysis and critically reviewed the manuscript.

Papathanassoglou, E. (60%) Williams, G., (5%) **Benbenishty, J., (35%) (2015) Research Advances in Critical Care: Targeting Patients' Physiological and Psychological Outcomes *BioMed Research International* Article ID 283067**

Julie Benbenishty conducted the literature review, contributed to research protocol development, interpreted the data and drafted the manuscript. All other authors contributed to interpretation of the data and critically reviewed the manuscript.

Editorials

Benbenishty, J., (100%) (2015) Family support group: a tool for nurses. *Nursing in Critical Care* 20; 282-3.

Julie Benbenishty was the sole author of this editorial

PUBLICATIONS NOT INCLUDED IN THESIS

Original Research

Ganz, F., **Benbenishty, J.**, Hersch, M., Fischer, A., Gurman G., Sprung, C.

(2006) The impact of regional culture on intensive care end of life decision making: an Israeli perspective from the ETHICUS study. *Journal of Medical Ethics* 32; 196-199.

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Contribution to Publication

Dear Christiane,

I am in the process of writing my PhD thesis of publications. The below joint paper is a part of my thesis. Can you please confirm that for the following publication my contribution was 50%?

Hartog, CS., (50%) Benbenishty, J. (50%) (2015) Understanding nurse-physician conflicts in the ICU. *Intensive Care Medicine* 41; 331-3.

Most Sincerely,

Julie

Pleaser insert you signature:

A handwritten signature in black ink, appearing to read 'C Hartog', written in a cursive style.

Christiane Hartog co-author

Contribution to Publication

Dear Elizabeth,

I am in the process of writing my PhD thesis of publications. The below joint paper is a part of my thesis. Can you please confirm that for the following publication my contribution was 50%?

Papathanassoglou, E. Williams, G., **Benbenishty, J. (35%)** (2015) Research Advances in Critical Care: Targeting Patients' Physiological and Psychological Outcomes *BioMed Research International* Article ID 283067

Most Sincerely,

Julie

Pleaser insert you signature:

[]

Elizabeth Papathanassoglou lead author

Contribution to Publication

Dear Jordan,

I am in the process of writing my PhD thesis of publications. The below joint papers are a part of my thesis. Can you please confirm that for the following publication my contribution was 80%?

Benbenishty, J., (80%) Hannink, J. (20%) Therapeutic Relationship between Nurses and recovering ICU patients. *International Journal of Human* no. 4 (2017): 208-213.

Benbenishty, J., (80%) Hannink, JR. (20%) (2015) Non-verbal communication to restore patient-provider trust. *Intensive Care Medicine* 41; 1359-60.

Most Sincerely,

Julie

Please insert your signature:



Jordan Hannink co-author

Contribution to Publication

Dear Ruth,

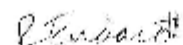
I am in the process of writing my PhD thesis of publications. The below joint paper is a part of my thesis. Can you please confirm that for the following publication my contribution was 20%?

Endacott, R., Boyer, C., Benbenishty, J., (20%) BenNunn, M., Ryan, H., Chamberlain, W., Boulanger, C., Ganz, F. D. (2016). Perceptions of a good death: A qualitative study in intensive care units in England and Israel. *Intensive and Critical Care Nursing* 36; 8-16.

Most Sincerely,

Julie

Please insert your signature:



Ruth Endacott, Lead author

Contribution to Publication

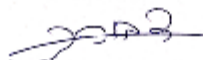
Dear Dvorah,

I am in the process of writing my PhD thesis of publications. The below joint papers are part of my thesis. Can you please confirm that for the following publications my contribution was 70% and 45%:

Benbenishty, J., (70%) Kirshbaum-Moriah, D., (25%) Harel C. (5%) Exploration of Nurse/Social worker ICU family support group intervention satisfying family members' needs. *Nursing in critical care* under review February 2019

Kirshbaum-Moriah, D., (35%) Harel, C., (20%) Benbenishty J. (45%) (2016) Family members' experience of intensive care unit support group: qualitative analysis of intervention. *Nursing in Critical Care* 21; 341-349.

Pleaser insert you signature:

A handwritten signature in blue ink, appearing to read 'Dvorah', with a horizontal line extending to the right.

Dvorah Kirshbaum-Moriah, co Author

Contribution to Publication

Dear Freda

I am in the process of writing my PhD thesis of publications. The below joint papers are part of my thesis. Can you please confirm that for the following publications my contributions were 15%; 70% and 65%:

Ganz, F.D., Raanan, O., Khalaila, R., Bennaroch, K., Scherman, S., Bruttin, M., Sastiel, Z., Fink, N.F.
Benbenishty, J. (15%) (2013) Moral distress and structural empowerment among a national sample of Israeli intensive care nurses. *Journal of Advanced Nursing* 69; 415-424.

Ganz, F. D., Endacott, R., Chaboyer, W., **Benbenishty, J., (15%)** BenNunn, M., Ryan, H., Spooner, A.
(2015). The quality of intensive care unit nurse handover related to end of life: A descriptive comparative international study. *International Journal of Nursing Studies* 52; 49-56.

Benbenishty, J., (70%) DeKeyser, F., Adam, S. (2005) Cultural differences of intensive care nursing in Europe. *Intensive and Critical Care Nursing* 21; 172-178.

Benbenishty, J., (65%) DeKeyser Ganz, F., Lippert, A., Bulow, HH., Wennberg, E., Henderson, B., Svantesson, M., Baras, M., Phelan, D., Maia, P., Sprung, C. (2006) Nurse involvement in end-of-life decision making: the ETHICUS Study. *Intensive Care Medicine* 32; 129–132.

Please insert your signature:



Contribution to Publication

Dear Freda

I am in the process of writing my PhD thesis of publications. The below joint papers are part of my thesis. Can you please confirm that for the following publications my contribution was 15%:

Ganz, F.D., Raanan, O., Khalaila, R., Bennaroch, K., Scherman, S., Bruttin, M., Sastiel, Z., Fink, N.F. Benbenishty, J. (15%) (2013) Moral distress and structural empowerment among a national sample of Israeli intensive care nurses. *Journal of Advanced Nursing* 69; 415-424.

Ganz, F. D., Endacott, R., Chaboyer, W., Benbenishty, J., (15%) BenNunn, M., Ryan, H., Spooner, A. (2015). The quality of intensive care unit nurse handover related to end of life: A descriptive comparative international study. *International Journal of Nursing Studies* 52; 49-56.

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FD Ganz, Lead Author

Contribution to Publication

Dear Freda

I am in the process of writing my PhD thesis of publications. The below joint papers are part of my thesis. Can you please confirm that for the following publications my contributions were 15%; 70% and 65%:

Ganz, F.D., Raanan, O., Khalaila, R., Bennaroch, K., Scherman, S., Bruttin, M., Sastiel, Z., Fink, N.F.

Benbenishty, J. (15%) (2013) Moral distress and structural empowerment among a national sample of Israeli intensive care nurses. *Journal of Advanced Nursing* 69; 415-424.

Ganz, F. D., Endacott, R., Chaboyer, W., **Benbenishty, J., (15%)** BenNunn, M., Ryan, H., Spooner, A. (2015). The quality of intensive care unit nurse handover related to end of life: A descriptive comparative international study. *International Journal of Nursing Studies* 52; 49-56.

Benbenishty, J., (70%) DeKeyser, F., Adam, S. (2005) Cultural differences of intensive care nursing in Europe. *Intensive and Critical Care Nursing* 21; 172-178.

Benbenishty, J., (65%) DeKeyser Ganz, F., Lippert, A., Bulow, HH., Wennberg, E., Henderson, B., Svantesson, M., Baras, M., Phelan, D., Maia, P., Sprung, C. (2006) Nurse involvement in end-of-life decision making: the ETHICUS Study. *Intensive Care Medicine* 32; 129-132.

Please insert your signature:



FD Ganz, Lead Author and co-author

Contribution to Publication

Dear Seema,

I am in the process of writing my PhD thesis of publications. The below joint paper is a part of my thesis. Can you please confirm that for the following publication my contribution was 75% and 80%?

Benbenishty, J., (75%) Biswas, S. (2015) Cultural Competence in Critical Care: Case Studies in the ICU. *Journal of Modern Education Review* 5; 723-728.

Benbenishty, J., (80%) Biswas, S. (2015) Developing Cultural Competence in Clinical Practice. *Journal of Modern Education Review* 5; 805-811.

Most Sincerely,

Julie

Please insert your signature:

[Seema Biswas]

Seema Biswas co-author

Contribution to Publication

Dear Hans-Henrik,


I am in the process of writing my PhD thesis of publications. The below joint paper is a part of my thesis. Can you please confirm that for the following publication my contribution was 15%?

Bulow, H., Sprung, C., Baras, M., Carmel, S., Svantesson, M., Benbenishty, J., (15%) Nalos, D. (2012). Are religion and religiosity important to end-of-life decisions and patient autonomy in the ICU? The Ethicatt study. *Intensive Care Medicine* 38; 1126-1133.

Most Sincerely,

Julie

Please Insert your signature:

A handwritten signature in black ink, appearing to read 'H. H. Bulow', is written over a yellow rectangular highlight.

Hans Henrik Bulow, lead-author

28th of March 2019.

